

DYING AND LIVING:
A MODEL FOR SPIRITUAL CARE IN A HOSPICE SETTING

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Linda Jean Lloyd

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LINDA JEAN LLOYD

has been presented to and accepted by the
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Faculty Committee

William M. Clements, Chairperson

Philip Clayton

Lourdes Arguelles

Dean of the Faculty

Sheryl A. Kujawa-Holbrook

May 2008



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Abstract

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Linda Jean Lloyd

Even though the hospice movement has existed in the United States for more than forty years, the practice of spiritual care as a hospice discipline continues to vary widely. Hospice, which began as a spiritual care movement, is becoming more bureaucratic and medical model oriented. The requirements for those providing spiritual care also vary widely from hospice to hospice. It is this writer's intention to look at the origins of the hospice movement, provide an overview of what other team disciplines have written about spiritual care, define spiritual care as it relates to ministry with the dying, offer some theological perspectives for understanding death and dying, and explore what it is like to be conscious of dying and of living with the realities of death and dying. A tentative model is offered as a means to begin to standardize the discipline of spiritual care as the other core disciplines have more standardized requirements. This is a time of great change in the hospice movement and it is important for spiritual care to remain a vital part of the care provided to dying people and their families who choose hospice.

With gratitude and love, I dedicate this work to

My Creators

Robert Bright Lloyd and Janice Hobbs Lloyd

My Redeemers

Christie Cozad Neuger and Philip Clayton

My Sustainers

Anne Marie Paton and Jacob Bradford Paton-Lloyd

and

those whom I have been privileged to accompany on their
journeys through dying and living

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INTRODUCTION

Even as a child I felt that there was more to this life than I could comprehend. I come from a line of deeply spiritual people, some of whom were missionaries and others who were healers. My parents and grandparents encouraged my inquisitiveness, especially regarding things of a spiritual nature. They were also willing to admit that they didn't know all the answers to the mysteries of death and life, and they relied on something they called faith. As I provide spiritual care to the dying and their loved ones, I am more certain than ever that there is more to dying and living than I understand. Yet from my childhood through the present, I continue to ponder the meaning of life and what comes next. Although the work I do has led to more questioning and grappling with the realities of death and life, it has also provided great comfort and helped me to understand the thing my parents called faith.

The ministry in which I engage is a sacred endeavor. People allow my colleagues and me into their lives at incredibly spiritual, sacred, and vulnerable times. Other than the birth of a child, what could be a more intimate

time in the life of a family? Journeying with those who are dying is a privilege. Each path taken is as unique as the individual taking it. Some of the mile stones may be similar but the path is created as the dying one walks it. To walk alongside for a time, is to be in the midst of the sacred. Spiritual care can be called by many names, or none at all, and has been a force in death and life since the beginning of recorded time.

Spiritual care has been an innate aspect of care for the dying throughout history. The roles of professionals providing spiritual care have evolved into diverse specializations, including those who provide this care in a hospice setting. A current survey of the literature, however, exposes the surprising reality that, even with all the advancements in palliative care over the last several decades, a common understanding of spiritual care in a hospice setting remains virtually undeveloped by pastoral care professionals. The purpose of this dissertation is to offer a model of spiritual care in a hospice setting in order to foster more intentional focus on this area of care by hospice professionals. No one really understands the

spirituality of the dying and I believe that it is the responsibility of spiritual care providers to delve into that mystery.

The modern hospice movement began in England in the 1950s and 1960s and was spearheaded by Cicely Saunders, who established St. Christopher's Hospice in 1967. The movement crossed the Atlantic to the United States where a pioneering hospice was formed in 1974, and today the growth and development of hospices across the United States continues with the creation of national associations like the National Hospice and Palliative Care Organization. While the original objective of hospice may have been to place spiritual care and pain management at its heart, the actual scope of practice of spiritual care in a hospice setting has been rather limited. Even though spiritual care is viewed as an essential component of core hospice philosophy and of the composition of the hospice "team," the practical application of spiritual care has remained vague at best. Since nurses and social workers have completed most of the research on spiritual care in the hospice movement, it is important that pastoral care professionals begin to add their voices to the discussion.

According to the accrediting agencies that regulate hospice standards of practice, a hospice must include a spiritual care provider as a member of the patient care team; however the understanding of what comprises spiritual care varies, as does the degree of specialization of the one designated as the spiritual care provider.¹

It is also interesting to note the differences and commonalties regarding theology and spiritual care practice among staff, patients and families, and the larger community. Intriguing questions such as how people view death and dying and what they think/feel will happen during and after death are calling for theological exploration. The larger community is still in need of basic education regarding the hospice movement, and the spiritual care component tends to be the most ambiguous piece. Most hospices tend to follow a medical model for their blueprint of practice. This translates to pain management and physical comfort measures becoming the focus of care where spiritual and psychosocial issues are considered secondary at best.

¹ The accrediting bodies include, but are not limited to, Joint Commission on Accreditation of Healthcare Organizations, Community Health Accreditation Program, as well as other local and national agencies.

It is the intention of this writer to explore the aspects of spiritual care in a hospice setting from a spiritual/pastoral care perspective in both literature and in the lives of those involved in hospice care. This will include reviewing with theological lenses how dying and living are perceived by patients, families, staff, and the larger community.

The argument made here is that there has been no standard for the provision of theological/spiritual care in a hospice setting. As a progressive, white female whose foundations include feminism, diverse theological perspectives, and academic privilege, I will be addressing my thesis through specific lenses. I am a professional chaplain who is deeply concerned with spirituality and the spiritual journeys of the dying and their loved ones. Process theology, including the work of Marjorie Suchocki, will be intertwined with theological guidance from Tibetan Buddhist Sogyal Rinpoche as the underpinning for stepping into the realm of dying and living. Elizabeth Kubler Ross' and Kenneth Doka's work on dying, bereavement, and spirituality will add dimension to the topic. A review of the history of the hospice movement in the United States

will preface and provide location for this discussion. This exploration will be limited by the setting and scope of practice that exists as hospice in the United States. By using the framework of hospice to explore spiritual care and concepts of death and dying, the focus is on terminal illness rather than traumatic death. Patients, families, and those involved in their care are offered the opportunity to examine death and dying as a process rather than an "instantaneous" occurrence. This work will also be limited in scope by the theological perspectives utilized. The Process Theology of Marjorie Suchocki and the Tibetan Buddhism of Sogyal Rinpoche have some threads in their use of metaphysics, even as they are culturally divergent. While *God, Christ, Church* by Suchocki² and Rinpoche Sogyal's *The Tibetan Book of Living and Dying*³ are at the center of this discussion, other writers' works will be reviewed as well. Alfred North Whitehead and John Cobb have contributed to the discussion with their work in process theology, while Christine Longaker and Margaret Coberly

² Marjorie Suchocki, *God, Christ, Church: A Practical Guide to Process Theology*, new rev. ed. (New York: Crossroad Publishing, 1989).

³ Rinpoche Sogyal, *The Tibetan Book of Living and Dying*, rev. and updated ed. (San Francisco: HarperSanFrancisco, 2002).

enhance the perspective of Tibetan Buddhism as it relates to hospice care. Other limitations include the specific interpretations this writer has of Process Theology and Tibetan Buddhism - viewing them from a particular world-view of an English speaking, Caucasian, North American female. As such, it is the common threads of metaphysics and spirituality that will be used as a catalyst for the theology explored in these writings.

This is a qualitative study, employing a phenomenological methodology, which intends to describe and conceptualize how spiritual care is defined and practiced in a hospice setting. The method employed in this research will be practical phenomenology based on the works of Patricia Brenner.⁴ Phenomenology is the examination of human experiences through detailed descriptions of the individuals being studied. The procedure involves studying a small number of subjects through extensive and prolonged engagement to develop patterns/relationships of meaning. A narrative method that incorporates living human documents is at the heart of this writing. It is this writer's intent to capture the richness of individual experiences of

⁴ Patricia Brenner, ed., *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (Thousand Oaks, CA: Sage Publications, 1994).

This model of care is tailored to the needs and wishes of patients and their loved ones.⁶ Hospice is a form of palliative care, or comfort care, that provides quality end-of-life experience, rather than curative care, which seeks physical healing and/or the prolonging of life.

The primary audience considered in this writing is composed of professionals involved with hospice care, as well as patients and their families. It is the intention of this writer to provide a better appreciation of what spiritual care involves and to offer some understanding of how we provide spiritual care to those who are dying as well as those who are left to ponder the questions of our existence. A secondary audience for this information might include those interested in exploring the theological dimensions of spiritual care for the dying.

It is striking that the exploration of spiritual care in a hospice setting has been limited and that other disciplines, such as social work and nursing may have contributed more to the investigation than those from pastoral/spiritual care professions. Writings regarding

⁶ National Hospice and Palliative Care Organization, "What is Hospice and Palliative Care," accessed 20 Aug. 2005; available from <http://nhpco.org/i4a/pages/index.cfm?pageid=4648>.

those dying and living on hospice service. A narrative method allows the realities and insights of individual patients and families to inform the theory and practice of spiritual care in a hospice setting.

Some of the major terms that will be used in these writings include: spiritual, spiritual care, pastoral care, religious, palliative, hospice, theology, phenomenology, process theology, Tibetan Buddhism, and dying process. One of the important tasks in this writing is to define the differences in nuance of terms that have very similar meanings. The terms "spiritual" and "religious" have distinct meanings yet are often used interchangeably, as are "pastoral care" and "spiritual care." According to the National Hospice and Palliative Care Organization, hospice is a model for quality, compassionate care at the end of life.⁵ Hospice care emphasizes pain and symptom management, and psychosocial/spiritual support. This care involves a team of professionals and volunteers who address the emotional, social, and spiritual needs of the patient and family.

⁵ National Hospice and Palliative Care Organization, "Hospice," accessed 8 Nov. 2007; available from <http://www.caringinfo.org/LivingWithAnIllness/Hospice.htm>.

spiritual care in the disciplines of social work and nursing will be examined because they have explored some aspects of spiritual care more than writers from other professions. The hope of this writer is to contribute to the discussion from a spiritual care perspective as a pastoral care professional with both academic and experiential training.

The chapters to be included in this exploration are as follows:

Chapter 1 - What is Hospice?

The modern hospice movement has several components and evolutions that are discussed, including a review of the standards of care. This chapter includes the history, evolution, and practice of the modern hospice movement.

Chapter 2 - What is Spiritual Care?

Spiritual care is inclusive and universal both in its potential scope and practice. It has a base that includes, but is not limited to, institutional ideologies. These would include "non-traditional" faith journeys and

practices such as Native American spirituality, panentheism, and wicca, as well as the undefined practices of those living without spiritual guidance. Pastoral care is a more focused form of spiritual care that is grounded in the spiritual traditions found in institutional religion. The practice of spiritual care is addressed and the diverse interpretations of scope of practice is explored. Works in process theology and Tibetan Buddhism act as tools for the exploration of dying and living from a theological perspective. Studies on the understanding of spiritual care in hospice are reviewed as well as Elizabeth Kubler Ross, Christine Longaker, Ira Byock and Kenneth Doka's work on dying and related issues.

Chapter 3 -- The Voices of Other Hospice Disciplines Regarding Spiritual Care

This chapter is compiled from the works of other disciplines involved in hospice care, particularly nursing and social work. A review of the contributions to our understanding of spiritual care in hospice from these professions paves the way for the formulation of a model from a spiritual care perspective.

Chapter 4 - Dying

This chapter includes a discussion of the dying process from a hospice perspective - looking at the biological, psychological, and spiritual components, and from the perspectives of those who are dying and those who are being left behind. Death and dying will be explored from different theological perspectives, particularly Process Theology and Tibetan Buddhism. These schools have in common an understanding that we are always in process. Exploring the concepts of death and dying as parts of a larger process will be helpful to build a foundation for a theological construct of what happens in the process of dying and after death.

Chapter 5 - Living

A discussion of the aspects of living from a hospice perspective - how people adapt to a terminal diagnosis, survivor's guilt, the effect dying has on those who remain, and the grief process comprises this chapter. An understanding of what "quality of life" means will be explored in this chapter as well.

Chapter 6 – A Model for Spiritual Care in a Hospice Setting

This chapter will offer constructive possibilities regarding a model for providing spiritual care in a hospice setting. The intention here is to make use of current theological suppositions as well as living human documents to shed light on the exploration of the spiritual care process. Theology grounds our hope of what will become of us after the adventure of this life becomes history and we turn to face the next stage in our journey. As spiritual care providers we can offer comfort for those asking very profound questions and seeking guidance/reassurance as they transition from this life into the next.

Conclusion

Some conclusions will be drawn from this exploration regarding the practice of spiritual care in a hospice setting. The benefit of using theological lenses will be reviewed and possible areas for future study will be outlined.

Everyone is involved in the spiritual process – doctors, nurses, home health aides, social workers, patients, and

families. Some of this process is conscious and intentional and some is not. Adding the voices of professionally trained spiritual care providers to the voices of other disciplines will enrich the understanding and provision of care for all involved. Infusion of an intentional sense of the spiritual through the discipline of spiritual care will only serve to enhance the sense of the sacred found throughout the movement. Our desire to enhance the quality of life of the dying and decrease pain and suffering are what bring all of us to this work called hospice. There have been moments in my life that have sharpened my awareness of the need for compassionate spiritual care that is influenced by the head, through academic and clinical training, and the heart, grounded in the sacred. Some of these experiences will be shared in the coming pages.

It is the intention of this writer to include my writing as a professionally trained and experienced spiritual care provider with those of other disciplines that have written about spiritual care in a hospice setting, and by doing so, represent a stronger spiritual care presence in the body of knowledge that defines hospice

care in the United States. I believe that it is imperative that the role of spiritual care provider be understood as a professional, academically trained position on the hospice team and that the voices of that discipline are heard. Trained spiritual care providers have unique contributions to make to the evolving movement of care for the dying called hospice.

CHAPTER 1

WHAT IS HOSPICE?

*Do not neglect to show hospitality to strangers, for
thereby some have entertained angels unawares.
- Hebrews 13:2 (NRSV)*

The first time I attended a death was during a Clinical Pastoral Education (C.P.E) experience in a very large hospital in Oklahoma.¹ I remember being very anxious as I began my first night on-call. I was afraid someone would die and I wouldn't know what to do. I was afraid someone would die and it would be very traumatic and dramatic and I wouldn't know what to do. I was afraid someone would die.

Someone did die. All of the pagers went off around me as I made rounds late that evening. I felt a sense of relief, until my pager finally sounded. When I responded to the page, I learned that a patient was dying, nothing more could be done, and the family was with the patient waiting for me. As I entered the curtain shrouded area around the man's bed, I had an immediate sense of calm. Everything seemed so quiet and peaceful as I joined the

¹ Clinical Pastoral Education offers those in ministry and those training for some form of ministry to use a clinical setting to enhance their skills and confront issues that might be challenging in a ministerial setting.

family during their final good-byes. We prayed softly and stood together as the blips on the heart monitor slowed and finally stopped. It was very, very quiet for a few minutes and time seemed as if it stood still. This was a sacred moment. Suddenly, it seemed, the hustle and bustle of the hospital intensive care unit jarred us out of that space and back into reality. A man had just died. The family thanked everyone and left. I went to the chapel and sat there taking in my first experience attending a death. It was profound and anti-climactic. It was momentous for me as my understanding of death and life deepened slightly. Providing care for the dying and living that night reminded me of one of the aspects of spirituality - authentic presence.

Care for the dying has existed for as long as humanity has been present on the earth. How that care has been manifested has evolved as humanity has developed. Birth and death have been perceived as mysterious, with birth being miraculous and death being ominous. Understanding the spirituality of care of the dying has always been challenging. Those who have assisted with these transitions from "mystery" to life and life to "mystery" have

traditionally been the healers/spiritual folk of the community. The hospice movement is a relatively new phenomenon with ancient roots. Hospice caring for the dying is intended to be holistic - caring for the whole human being: body, mind, and spirit.

Hospice care follows a medical model in the western world, particularly in the United States. Similarly, the literature spanning this movement is diverse and has focused on the more clinical aspects of care. Spiritual care goes beyond the clinical realm and embraces all aspects of the life of a patient, including his/her support systems. In order to understand the dynamic aspects of spiritual care in a hospice setting one must first understand what hospice is. This process includes a review of the history, evolution, and practice incorporated in the hospice movement.

The term hospice originates from the Latin word *hospes*, meaning both host and guest. According to Webster's Dictionary, "hospice" has two definitions:

1. A lodging for travelers, young persons, or the underprivileged especially when maintained by a religious order;

2. A facility or program designed to provide a caring environment for supplying the physical and emotional needs of the terminally ill.²

The etymology of hospice is also shared by the terms "hospital" and "hospitality", two words that share origin yet today are very divergent in meaning and understanding. How many people would consider hospitals hospitable places to be? While hospitals are places where people go to deal with traumas and undergo curative and cosmetic medical treatment, the emphasis is on the healing of the body and is a very scientific matter. Even many in the medical community are uncomfortable with the realities of death, which contributes to a culture in the United States that has become fixated on youth and lives in denial of death. This phenomenon may change as the hospice movement changes our concepts of death and dying.

Although the first hospital, Epidaurus, was built by Greek physicians in the fifth century B.C.E., it was more like a spa than a hospital. Epidaurus was definitely not a place to heal from serious illness or to die. Even though the hospice movement may have originated as long ago as 2000 years, it is not possible to determine exactly and

² Merriam-Webster Online, s.v. "Hospice," 2005 ed.; accessed 20 Aug. 2005; available from <http://www.Merriam-Webster.com>.

where and when the movement began. It is possible to acknowledge the spiritual roots of work with the dying. In C.E. 361, Roman Emperor Julian the Apostate complained about a Roman matron named Fabiola, a Christian, whose home had become a place of refuge. She offered hospitality, rest for weary pilgrims, a place for healing and comfort of those who were ill, and a place of care for those who were dying.³ While hospitality was an integral part of the house church during the formation of the early Christian Church, there was no organized movement of hospice care until the 11th century C.E. The first formal records of hospice care were those of the Hospitaller Knights of St. John of Jerusalem.⁴ They were considered one of the most important of all the military orders, both for the extent of the geographic area they covered and for their duration - existing before the Crusades and continuing into the present time even as they have undergone several evolutions. Known as Hospitallers of Jerusalem until 1309, the members were called Knights of Rhodes from 1309 till

³ Sandol Stoddard, *The Hospice Movement: A Better Way of Caring for the Dying* (New York: Stein and Day, 1978), 21.

⁴ Stoddard, 26-30.

1522, and have been called Knights of Malta since 1530.⁵ The knights in this order were relegated to different responsibilities constituting three classes: the military brothers, the brothers infirmarians, and the brothers chaplains. The infirmarians were the ones who provided care to those who were ill and dying on the island of Rhodes during the early Crusades and continuing through transitions to the island of Malta over two hundred years later.

The concept of hospice continued to spread throughout Europe during the middle ages. Religious orders established "hospices" at key crossroads on the way to religious shrines like Santiago de Compostela, Chartres and Rome. These shelters helped pilgrims, many of whom were traveling to these shrines seeking miraculous cure of chronic and fatal illnesses, and many of whom died while on their pilgrimages. As the Age of Enlightenment ensued, a greater emphasis was placed on scientific study, including medicine. It remained the responsibility of spiritual care providers to care for the dying, and religious orders

⁵ Nihil Obstat and Remy Lafort, eds., *Catholic Encyclopedia* Vol. 4, [book online] (New York: Robert Appleton, 1908; accessed 20 Aug. 2005), s.v. "Crusades," by Louis Bréhier, transcribed by Douglas J. Potter; available at www.newadvent.org/cathen/24543c.htm.

offered care to the sick and dying in local or regionally based institutions. Most people died at home cared for by the women in the family.

By the nineteenth century, several transformations had taken place. Madame Garnier of Lyon, France opened a place of respite to care for the dying. In 1879 Mother Mary Aikenhead of the Irish Sisters of Charity opened Our Lady's Hospice in Dublin, caring only for the dying. Toward the end of the 1800s, there was an increase in the institutionalization of care that, coupled with the growth in medical knowledge, encouraged the western medical model to begin its evolution. In 1905 the Irish Sisters of Charity opened St. Joseph's Hospice in East London, followed by the opening of two more hospices in London.

Another aspect of the hospice movement began in the 1930s - the study of the psychosocial aspects of dying and bereavement. By the 1950s over 80% of people dying in the United States were dying in hospitals or nursing care facilities. Meanwhile, across the Atlantic, physician Cicely Saunders was founding the modern hospice movement. She worked at St. Joseph's Hospice from 1957-1967, studying pain management in patients with advanced cancer.

Saunders, who trained as a nurse and social worker, pioneered the use of opioids by giving medication on a regular schedule rather than when pain occurred. She pioneered modern palliative care at St. Christopher's Hospice which was opened in London in 1967. Here the concepts of pain management and an inter-disciplinary team approach to caring for the dying were revolutionized. Saunders believed in an approach that included the regular use of opioids to control physical pain and consideration for the spiritual and emotional well being of patients and families. The hospice movement spread throughout Great Britain and found its way to the United States in 1974. Saunders collaborated with a team of professionals from Yale, Connecticut and the surrounding area and New Haven Hospice was formed. Now known as Connecticut Hospice, it began at the behest of Edward F. Dobihal, Jr., Clinical Professor of Pastoral Care and Florence S. Wald, Dean of Nursing at Yale University. This transition across the Atlantic also saw a shift from a spiritually driven, medically informed hospice practice to a medically driven, somewhat spiritually informed hospice practice.

Florence Wald and Elisabeth Kubler-Ross pioneered the field of end-of-life care in the 1960s and 1970s. Wald studied with Cicely Saunders at St. Christopher's and Kubler-Ross was a medical doctor in Chicago working with the dying. Florence Wald was one of the founders of the first hospice in the U.S. and Kubler-Ross wrote *On Death and Dying*,⁶ relating the five stages of grief most terminally ill patients experience. Their passion and concern spread throughout the United States as hospices were formed to provide compassionate palliative care to the dying and their families.

In 1984 Medicare added a hospice care benefit. The types of illness treated with palliative care have continued to expand and now include cancer, dementia, amyotrophic lateral sclerosis, Acquired Immune Deficiency Syndrome, Chronic Obstructive Pulmonary Disease, and Congestive Heart Failure as well as other diagnoses. Over the last decade the number of hospice and palliative care programs has risen to over 3000 and is still growing. The movement now circles the globe.

⁶ Elisabeth Kubler-Ross, *On Death and Dying* (New York: Simon and Schuster, 1986).

Looking at this brief history of the hospice movement, one can sense the thread of spiritual care woven through it. The spiritual leaders in many communities were also the healers.⁷ In the early Judeo-Christian tradition, as roles became more specialized, the care of the dying was the responsibility of the widows. As the Christian church evolved, the roles in the church hierarchy became more formalized and women were relegated to teaching, praying, and caring for the infirmed. During the Middle Ages and the Enlightenment as medicine became more refined and its practitioners began to be perceived as professionals, the distinction between curing and healing became more pronounced. The Greek concept of a mind(soul)/body split solidified with the work of Thomas Aquinas. This duality has resulted in the medical model focus on the body, and perhaps the mind, but with no consideration for the soul/spirit.

Lack of care for the whole human being was of great concern to those initiating the modern hospice movement. Cicely Saunders was acutely aware of the need for pain

⁷ L[arry] K[ent] Graham, "Healing," in *Dictionary of Pastoral Care and Counseling*, ed. Rodney J. Hunter, et al. (Nashville: Abingdon Press, 1990), 498.

management and the reduction of physical suffering in terminally ill patients. She was also aware that pain went beyond the physical, and that emotional and spiritual pain needed to be addressed as well. The concept of an interdisciplinary team was integral to the early philosophy of hospice care. It remains so today, even in an increasingly medically modeled approach to care.

The hospice programs in the United States may be distinguished according to the base of their activities. Community-based hospice programs have their primary locations either in freestanding units or in the offices that serve the members of the hospice care coordinating team while the patients reside at home, skilled nursing facilities, or group homes. Institution based hospice groups are typically located in acute care facilities. Other models of hospice and palliative care exist, including those organized by the Visiting Nurse Association, programs affiliated with nursing homes, and volunteer hospice programs. Hospice care can be for-profit, not-for-profit, or volunteer based. Each hospice has its own unique characteristics, regardless of the means for reimbursement for services. All hospices have the same

concerns regarding the issues facing hospice care. These issues include the feasibility of each model, concerns about professional resistance from medical practitioners and others in the community, financial concerns, means for evaluation, regulations and oversight, and opportunities for innovation.⁸

So, what is hospice in its modern day incarnation? It is a form of palliative care that intends to empower people to live fully and die well, with as much dignity and as little pain as possible. In defining hospice the National Hospice and Palliative Care Organization (NHPCO), states:

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.⁹

Palliative care is defined as:

treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from

⁸Charles A. Corr and Donna M. Corr, *Hospice Care: Principles and Practice* (New York: Springer Publishing, 1983), 379.

⁹ National Hospice and Palliative Care Organization, "What is Hospice and Palliative Care?" X

consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual's needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual's values and symptoms. The individual's choices and decisions regarding care are paramount and must be followed.¹⁰

These definitions of hospice and palliative care are shared at the national, state, and local levels to insure consistency in adhering to the standards of care for hospice. However, each hospice has its own unique characteristics and energy, as the following living human document demonstrates.

Beth

Recently, a woman and her adult daughter came through the door at the office. The woman had remembered meeting me when I did a presentation for her church group about hospice. They were now at a difficult crossroads. The daughter was distraught at learning that her father had a terminal illness. This mother-daughter team was attempting

¹⁰ National Hospice and Palliative Care Organization, "Hospice Philosophy Statement," accessed 20 Aug. 2005; available at <http://nhpco.org/i4a/pages/index.cfm?pageid=5308>.

to find the best support system for their loved one. The mother, "Susan," and daughter, "Beth," were reeling with the shock that facing a terminal diagnosis causes in an individual or family system. Susan was present to support her daughter and discover what needed to be done for her ex-husband's care. Beth was attempting to discern what she would need to do in order to make sure that her father got the best care that he could possibly receive. They'd been in touch with another hospice/home health agency and were looking for more information, and alternatives. We talked for a while, and I discovered that Beth was contemplating moving her life across the country to care for her father in his final days. Susan had some understanding of what hospice was about because of our interaction a few months earlier. I listened to Beth's story of her father and his new wife and Beth's concern that he receive the best care possible. She knew that her father would need help, in that he would be resistant to the idea of hospice. We talked about her concerns regarding her father and uprooting her life, and I sat with her while she cried. Beth and Susan left the office with information about hospice, including Medicare benefits and materials on the

dying and grief processes. I encouraged them to continue to discuss all the possibilities and contact us for any support we could provide. These two women had a great deal to consider and major decisions to make in the coming days.

These women are an example of a family, traumatized by a recent terminal diagnosis, which literally walked in off the street to begin their hospice education. While there are many hospices to choose from, not all provide the same standard of care. This family was given information and encouraged to talk with their loved one and their physician and to contact the agency for additional support. There are folks coming through the front doors daily, trying to find answers to their questions and support for their loved ones. The standards of care set out by the governing agencies allow some room for interpretation by the agency providing service, which may result in variances in the quality of care provided.

According to the guidelines for hospice care, the process involves a family member or designee who serves as the primary caregiver and may make decisions for the terminally ill person if necessary. Members of the hospice staff make visits to assess the patient and provide care

and services. Hospice staff members are available twenty-four hours a day, seven days a week. The hospice team develops a care plan to meet the needs of every patient regarding pain management and symptom control. According to guidelines, the hospice team typically includes: the patient's physician, a hospice physician or medical director, nurses, home health aides, social workers, clergy, trained volunteers, and alternative therapies as needed (nutrition, speech, etc.). This interdisciplinary team is responsible for: managing the patient's pain and symptoms; assisting the patient and family with the emotional, psychosocial, and spiritual aspects of dying; providing needed drugs, medical supplies, and equipment; instructing the family on patient care; providing other therapies; facilitating inpatient care; and providing bereavement services to loved ones.

The NHPCO includes the following information on its website for those inquiring about quality hospice care:

To ensure that end-of-life wishes are honored, nothing is more important than planning. Discuss your wishes with family, loved ones, and friends - and your health care providers. Begin the conversation. Hospice can help.

Despite enormous medical advances, too many Americans still die alone or in pain. Too many endure costly and ineffective treatments. And patients at the end of

life are being referred to hospice care too late, or not at all.

National Hospice Foundation research on end-of-life care found that Americans are more willing to talk about safe sex and drugs with their children than to discuss end-of-life care with their terminally ill parents. Only 24% of Americans put into writing how they want to be cared for at the end-of-life. A substantial proportion, 19%, have not thought about end-of-life care at all, while 16% have thought about it, but not told anyone their wishes.

The National Hospice and Palliative Care Organization estimates that for every one hospice patient, there are two more who could benefit from hospice services.

The Medicare Hospice Benefit guarantees comprehensive high-quality end-of-life care - at little or no cost - to America's terminally ill Medicare beneficiaries and their families.

National Hospice Foundation research shows that the top four services Americans feel are most important for a loved one who has less than six months to live are:

Someone to be sure that the patient's wishes are honored; Choice among the types of services the patient can receive; Pain control tailored to the patient's wishes; and Emotional support for the patient and family.

The NHF research showed that 80% of Americans said their wish is to die at home. Of the 2.4 million Americans who die each year, less than 25% actually die at home. Of the 700,000 patients who receive hospice care, over 75% die at home.

In addition, the research found that people are willing to have an outside organization come into their homes and assist with care for a family member in the last stage of life. Sixty-six percent would welcome help from an outside organization, like a hospice, while 24% would prefer to take care of the

family member by themselves, with the help of family and friends.

Today, there are nearly 40 million seniors in the U.S. In the next 30 years, that number is expected to double, as baby boomers reach age 65. Considering the discussions taking place in the media, online, and in other arenas, these boomers will place importance on dying well, just as they have emphasized living well. Hospice provides the quality care that allows people to live well at the end of life.¹¹

The National Hospice and Palliative Care Organization (NHPCO) began in 1978 as the National Hospice Organization, changing its name in 2000 to encompass the larger palliative care movement. Over 80% of the hospices in the United States are members of NHPCO, and as such, are encouraged to follow the guidelines recognized by the organization. This national not-for-profit organization is involved in research, education, networking, support, and advocacy for hospice and palliative care agencies and the people they serve. While membership in NHPCO is voluntary, hospices may be required to adhere to the regulations set forth by state and national agencies. In order to receive Medicare reimbursement for services, hospices need to be accredited by either Community Health Accreditation Program

¹¹ National Hospice and Palliative Care Organization, "Keys to Quality Hospice Care," accessed 20 Aug. 2005; available at <http://nhpco.org/i4a/pages/index.cfm?pageid=3303>.

or Joint Commission on Accreditation of Healthcare Organizations or directly by the state and Medicare. These agencies follow the same guidelines NHPCO sets forth for providing quality hospice and palliative care.

These standards mandate a team approach in the provision of hospice and palliative care. The team is comprised of qualified professionals and volunteers who provide a network of care meant to alleviate suffering and enhance the quality of life of the patient and family. These team members, mentioned earlier, work in a supportive and interdisciplinary manner.

Although each hospice follows its own protocol for admitting patients to service there is a similar flow to the process since they adhere to the same hospice regulations. Most agencies begin the admission process by receiving a referral for services. This referral may come from a family member, a doctor's office, a care facility, hospital, or even the patient. When someone is referred for service, an intake person and admission nurse make the initial contact. The admission nurse assesses the potential patient to determine what the care needs are, explains the hospice concept, and works with the patient

and care providers to complete the documentation required to place someone on hospice service. The initial care provisions may include equipment, medication, relief of physical pain, and a determination of what other hospice services may be desired.

The admission visit is followed within 48 hours by a visit completed by a registered nurse (RN). The visit provides an opportunity to obtain more information about the patient and family as well as assess the first 48 hours of care. A physical assessment of the patient is done again, comfort measures are evaluated, and a review documentation and explanation of the other services are provided. After the 48-hour visit is completed, an initial plan of care is created for the patient that is reviewed by the entire interdisciplinary team. The plan includes all the initial needs identified for the patient and family: plans/frequency of visits, treatment, supplies, equipment, medication, nutritional needs, and level of care. The plan of care is reviewed and updated every other week unless a need for review occurs sooner. Interdisciplinary team meetings are held to review patient care and discuss any changes or concerns. These discussions result from ongoing

interaction with the patient and family by team members to ensure that appropriate treatment modalities are used for physical, spiritual, and psychosocial needs. Many patients utilize the skills of all the team members, as shown in the following living human document.

Phil

Phil's wife had been on service with our hospice and had died about a year before the family requested services for Phil. Even as Phil had adapted to life without Marie, he still missed her terribly after having been married over 50 years. His adult children had provided for a paid caregiver, Abigail, to live with Phil. Abigail had cared for Marie until she died, and had been "keeping an eye" on Phil for the family ever since. Abigail moved in to the house after Phil was hospitalized with congestive heart failure. She took care of Phil alone for a couple of months until he was placed on hospice service. When hospice was first called in, Phil was seen by the nurse about once a week. The social worker and spiritual care provider visited with Phil and Abigail once or twice a month. There was no need for additional services at that time, so none were provided. As Phil's health

deteriorated, the numbers of visits by team members already involved in his care were increased. Additional support was made available in the form of a home health aide who assisted with Phil's personal hygiene needs. The change in Phil's status required continuous assessment and review of his care plan. New medications and equipment were ordered, additional supplies were used, and visit frequencies were increased in order to monitor Phil's condition and offer support to Phil and Abigail. Team members worked together to provide a strong network of care and compassion as Phil grew weaker. The team focused on keeping Phil comfortable even as his status changed. The hospice addressed his physical needs using medication, hands on care, equipment and supplies. The hospice addressed his psychosocial needs by visiting more often as he became homebound. It addressed his spiritual needs by encouraging him to participate in life review. Phil really enjoyed telling stories about the work that he did, the cars that he had fixed, what it was like growing up, and especially, about his beloved wife and children. He adored Abigail, and she was very fond of him. We spent time with her as well, reducing her anxiety, listening to her concerns, and

supporting the excellent care she provided for Phil. After Phil died we provided bereavement support to Abigail and his children, just as we had for Phil after Marie's death.

As Phil's story demonstrates, the interdisciplinary teams are comprised of several specialists who work together to provide a wide range of services to patients. The team continuously assesses needs and modifies services as necessary.

Accredited hospices are mandated by Medicare to provide bereavement services for thirteen months following the death of a patient. Each hospice can interpret this requirement in its own way, depending upon philosophy, resources, and the population served. Ideally, bereavement assessment begins at the time a patient is admitted to service. The patient and family are supported in coping with their grief even as the dying process unfolds. All team members are encouraged to use their skills and experience in supporting the families during this most difficult time. After the death has occurred team members are encouraged to contact family members with whom they have built a rapport. Condolence cards are signed by team members and mailed shortly after the death. An initial

condolence call is made by a member of the team and/or the bereavement staff. A bereavement packet containing a letter of support, informational booklets, and strategies for coping is mailed out within the first month following the death. The bereavement staff and volunteers contact family members by phone and mail follow up letters and information about every three months, until 13 months after the death. Once the cycle of bereavement is completed with the family they may be requested to complete a survey so that an assessment of services can be done.

During conversations with family members they are assessed to determine how well they are coping, encouragement is given to them to seek support, and they are provided with resources in the community including hospice bereavement support groups. If it is clear that someone is not coping well, especially soon after the death occurs, bereavement staff will either attempt to make a personal visit to them or encourage them to come to the office and meet with a member of the team. Sometimes it is more prudent to assess individuals face-to-face so body language, nonverbal cues, and physical presentation can be observed visually.

The spiritual care and bereavement departments also provide support by officiating at funerals and memorial services, facilitating semiannual, hospice sponsored memorial services, and offering educational and outreach support to the community.

Spiritual care of the sick, especially the dying, presents unique challenges to spiritual care providers. According to the *Dictionary of Pastoral Care and Counseling*, spiritual care of the sick has a rich and varied tradition and usually includes theories and practices developed around Word and Sacrament, the use of psychologically informed clinical methods, and an understanding of communal suffering.¹² Modern understandings of pastoral care of the sick encourage viewing an individual in a holistic manner and including the body, mind, and spirit in interpreting illness/sickness.

Upon reflection, it can be seen that the hospice movement incorporates several aspects that highlight it as medical innovation. The movement represents a shift from curative to palliative care, acknowledges the psychosocial

¹² David C. Duncombe, "Pastoral Care of Sick," in *Dictionary of Pastoral Care and Counseling*, ed. Rodney J. Hunter, et al. (Nashville: Abingdon Press, 1990), 1166.

and spiritual effect terminal illness has upon the patient and family, and it provides continuous comprehensive care. There continue to be challenges that need to be addressed in the evolution of the hospice movement as well. These challenges include educating healthcare professionals and the community at large about palliative care for the terminally ill, as there continues to be a lack of support for a philosophy that contradicts our society's emphasis on the preservation of life. Another challenge is providing the holistic care that is necessary to support a patient and family. The larger healthcare system also makes it difficult to provide the continuous comprehensive care that defines the hospice movement.

When given the choice, most people say that they would rather die at home. Dying at home surrounded by family was the norm in the United States during the early part of the last century. Families cared for loved ones who were dying and did so with little or no professional support. Dying was perceived as a part of the life process. Today, we are a culture that appears to consider death as optional. It is not. In many ways we insulate ourselves from the realities of death and dying. When a family invites a

hospice team into their home, they are also inviting in the possibility of dealing with death and dying in very tangible ways. They are inviting in opportunities to delve deeper spiritually, to love more fully, and to complete unfinished business. These are the processes that hospice care supports.

CHAPTER 2

WHAT IS SPIRITUAL CARE?

I don't know what your destiny will be, but one thing I do know: the only ones among you who will be really happy are those who have sought and found how to serve.

- Albert Schweitzer¹

When I visit with patients and families I am often asked what it is that I do. Every other member of the hospice team interacts with the family by doing something. Generally, the nurses check vitals and monitor comfort, the home health aides provide personal care, and the social workers complete documents and support arrangement for additional services. When asked what I do I reflect it back to the person asking to find out what they think my role with them is. This is the beginning of building a relationship with a patient and family. Some folks have pretty traditional concepts of spiritual care and expect me to pray with them, which I will do. Others are not so sure why I am there. At some point I usually tell them that I think I have the best job of all on the hospice team

¹ Quoted in Frederic Brussat and Mary Ann Brussat, *Spiritual Literacy: Reading the Sacred in Everyday Life* (New York: Touchstone, 1996), 323.

because I do not have to "do" anything with them. I get to come and simply "be" with them. By spending time together we can build a relationship which includes the spiritual components of trust, compassion, and love. Even though all relationships are not easy, they are all sacred and need to be honored as such. Some individuals remained angry or closed through their entire end-of-life process and they have the right to live and die in their own way. Others find peace quickly or want to converse more deeply about their spirituality and sense of the divine. I have learned that one of my most important spiritual practices with patients and families is to simply meet people where they are with an authentically non-judgmental and compassionate presence.

In order to understand how spiritual care fits into the modern hospice movement, one must discern what spiritual care is. A first step is to explore understandings of the components of spirituality. Spirituality is the way in which one understands and lives life in view of her/his ultimate meaning, beliefs, and values. It is the unifying and coalescing aspect of one's life and, when lived intentionally, is experienced as

increasingly pervasive and amalgamated – a process of growth and maturity. It integrates, unifies, and the whole of a person's life, defines the core values, establishes the fundamental basis for the individual's relationship with others and with society, includes a sense of the transcendent, and is the interpretive lens through which the person sees the world. It is the basis for community, for it is in spirituality that we experience our co-participation in the shared human condition. It may or may not be experienced in religious terms.

Spiritual care focuses on the whole human being, especially that aspect which is the driving force – the intertwining of the physical, emotional, and spiritual encompassing our individual and collective experiences. Spiritual care transcends the boundaries of religion, and perhaps even theology.

Spiritual care is a larger construct under which pastoral care is located. The *Dictionary of Pastoral Care and Counseling* discusses pastoral care at length, including contemporary methods, perspectives, and issues, as well as history, traditions, and definitions. In defining the

pastoral role in a hospice setting, Carol Brainerd (a nurse) writes:

the spiritual concerns of some hospice patients include a desire to participate in meaningful rituals, sacraments, or resources of the church. For many, spiritual needs are expressed as a struggle with the meaning of death, the meaning of suffering, life after death, or guilt and forgiveness.

The pastoral role with the terminally ill, therefore, is often twofold. It may be one of offering comfort and consolation through the administering of sacraments, scripture reading, or prayer for those who have established these rituals as ones that bring comfort and consolation; it may also be one of enabling the patient or family to explore questions of purpose and meaning.²

Pastoral care can be understood as a religious ministry carried out by ordained clergy. The tendency has been to follow the practice of some organized religion and explore spirituality from that vantage point. Spiritual care is inclusive and universal both in its potential scope and practice. It has a base that includes, but is not limited to, institutional ideologies. Those who practice spiritual care often do so from a pastoral care perspective. Spiritual care encompasses our need and desire to understand our connectedness to the self and other, regardless of the framework of that relationship.

² C[arol] Brainerd, "Hospice," in *Dictionary of Pastoral Care and Counseling*, ed. Rodney J. Hunter et al. (Nashville: Abingdon Press, 1990), 536.

Wayne Muller illustrates this point well in *Touching the Divine*.

There are times in all of our lives when we are forced to reach deep into ourselves to feel the truth of our real nature. For each of us there comes a moment when we can no longer live our lives by accident. Life throws us into questions that some of us refuse to ask until we are confronted by death or some tragedy in our lives. What do I know to be the most deeply true? What do I love and have I loved well? Who do I believe myself to be and what have I placed on the center of the altar of my life? Where do I belong? What will people find in the ashes of my incarnation when this is over? How shall I live my life knowing that I will die? And what is my gift to the family earth?³

Everyone has a spirituality, regardless of her/his level of religiosity. Everyone on the hospice team has a spirituality, a grounding core to his or her entity. Spiritual care can be conscious or unconscious just as one's sense of spirituality can be conscious or unconscious. The responsibility of all who provide spiritual care is to do so with compassion, grace and integrity. The spiritual process of dying is very sacred and is unique to the individual who is dying. One of the ways to gain insight into this process is by listening to and participating the life stories and dying processes of

³ Barbara S. Derrickson, "The Spiritual Work of the Dying: A Framework and Case Studies," *Hospice Journal* 11, no. 2 (1996): 13-14.

hospice patients and their families. In assisting the terminally ill and their dying processes, several aspects of spiritual work may be highlighted: remembering, reassessing, reassuring, and reunion.⁴ Perhaps the best way to illustrate this is through the use of living human documents.

When folks are faced with the finitude of their current existence by the reality of terminal illness, one of the tasks that is undertaken is life review. People reminisce and take stock of their lives by recalling relationships and events in their lives that have been meaningful. They may also be seeing meaning for their lives and a reason for hope.⁵ The following four situations provide examples of how people used life review, the process of remembering, to make an accounting of their lives.

Peter

Peter was actively dying when I met him in the skilled nursing facility. His family surrounded him, and these loved ones were maintaining a constant vigil at his bedside. The chaplain of the facility was happy to report

⁴ Derrickson, 11-30.

⁵ Christine Longaker, *Facing Death and Finding Hope* (New York: Doubleday, 1997), 26.

that Peter and his wife had been "led to Jesus" only a few days before. I was asked to visit by a hospice nurse who was concerned because Peter appeared to be extremely anxious and agitated and the typical pain management techniques were unsuccessful. Although Peter could no longer speak, I listened as his wife of 45 years shared their story with me. They met and fell in love as teenagers in the Netherlands, immigrating to this country after Peter finished school. Life had always been hard, yet they always had each other. Letting go was incredibly difficult for them both. As Peter exhibited signs of agitation, I showed his wife and daughter how to soothe and comfort him using healing touch techniques. This helped to some degree. Peter's brothers arrived and were concerned about having to leave the country before he died. They all talked about how strong he had always seemed, yet how uncomfortable the thoughts of dying made him. I explained to them that, even though he couldn't speak, Peter could still hear. They gathered around the bed and after praying together, I left as they continued reminiscing with Peter and one another as a means of finding comfort and solace.

Peter remained agitated and died the next day without regaining consciousness.

Betsy

I had heard about Betsy before she arrived for a respite visit at the hospice. She had been in a few times before and was, apparently, quite a character. Betsy was about 35 years old and had uterine cancer that had metastasized to her intestines. Betsy asked to see me and I was introduced to her mother as well. Betsy's mother left the room so we could talk. I listened as she told me how life had been going along okay until she was diagnosed. Betsy and her sister had grown up with their mother after their father left, a situation that was still painful to remember. As I listened, I learned that Betsy was searching for love and acceptance and that she had always wanted to have children. She cried as she talked about dying and then spoke hopefully of finding a way to beat the cancer. She had finished eating breakfast before I arrived and admitted that she had to vomit as she couldn't keep anything down anymore. This was one of the reasons her boyfriend had taken her back to her mother's house. He was unable to care for her and she had been bouncing back and forth between households for some time. While he never

came to visit her, her mother remained an almost constant presence during her time on the unit. It was around Halloween, and Betsy got energized as she planned to dress up for the hospice's annual party. She came as a witch and talked with everyone about how good she was feeling. Even though the cancer had spread throughout her body, Betsy was not willing confront that reality. She left the unit in the company of a doctor known for giving patients false hope. This appeared to be a pattern that Betsy had with the men in her life: her father, her boyfriend, and her new doctor.

Mary

Mary lived with her husband Stan and was receiving hospice care at home. Her only child, Sue, and Sue's adult children were there to care for Mary and Stan. Mary told me about her life and how she loved to swim when she was younger. An artist, Mary admitted to not remaining connected to the religion of her youth, and needed to speak with me privately. After the family left the room, Mary cried about the pain in her life and her disconnect from church because of an abusive experience. She was anxious about what would happen to her soul when she died because of this fractured relationship with the church. Mary

admitted to never having told anyone what had happened to her. I asked her about her sense of God. She said she hoped God loved her and that she would find peace. Mary spoke of the love she had shared with her family and the great joy her grandchildren brought her. She made a connection between this love and the love she hoped God had for her. Then Mary smiled at her own epiphany.

Fred

Fred lived in a skilled nursing facility where he helped provide pastoral care to the other residents. During my visits with Fred, he participated in extensive life review. He talked about how God had always been present in his life, from the time that his parents died and he rode the "orphan train," to the present in his current ministry. Fred talked about the hard times and the wonderful blessings he had received. Fred relayed a story about praying after finding out that his wife had cancer. He asked God to spare her and to take him instead. Fred believed that God did spare her and him so that they could continue to witness. This was a man who had endured immense hardships, yet still believed in goodness of God and life. Fred continued his ministry, even when confined to bed, until he died in his sleep.

These stories exemplify how life review encouraged new understandings of suffering and hope for these individuals during the dying process. While Peter couldn't participate in a life review, his wife found a great deal of comfort in sharing their story. She took the opportunity to thank Peter for his love and the life and shared together. Betsy was in a different place with her life review. She was reliving some of the pain of the past and desperately seeking ways to have a future. In fleeting moments, Betsy faced her prognosis and imminent death, yet most of the time she lived in denial of her physical reality. Mary was surrounded by love, yet harbored a secret that was causing her a great deal of spiritual pain. Once she was able to address that pain and let it go she found a great sense of peace. Fred had an exuberance for life that lit him up from the inside out. Even though life had never been easy for Fred, he managed to make the best of it by relying on his relationship with God. This relationship helped Fred to live fully and to die well. It is obvious that life review is an essential component of the dying process. Viewed from a spiritual care perspective, life review affords the patient and/or family

the opportunity to make peace with dying and prepare consciously for death.

Life review can help individuals and families take an accounting that allows for an overarching sense of the value of the life that has been lived. If the life has been lived well and fully in the eyes of the one(s) participating in the life review, a sense of goodness and peace can prevail. If the life leaves a sense of incompleteness, of not being lived well, or of having regrets, and if the issues are not resolved then the dying process may be one of struggling and anxiety. Life review offers the opportunity to put closure on the life lived and offers the possibility for dying peacefully. As a spiritual care provider, I have had the opportunity to be present with individuals and families as they come to terms with this major transition called death. I am always curious and interested to hear people's life stories. They not only give me a sense of who people are, they allow me to build relationships and to discern where they are in dealing with the dying process.

As human beings, we are constantly involved in the process of assessing and reassessing that which defines us

and our sense of values. Terminal illness alters our sense of who we are and what defines us in the world. Our sense of identity can undergo radical change, as our ability to interact undergoes transformation. This is more acutely disruptive in those who have externalized their sense of identity and only understand themselves to be valued for the roles that they have played. The following living human documents provide examples of the profound effects these value transitions play in our lives.

Rachel

Rachel and Herman had been married for over 50 years when Herman was admitted to the hospice program. Herman had had Parkinson's disease for several years and his condition continued to deteriorate. During this time, Rachel had been the sole care provider. She washed and bathed him, cooked for him and fed him, cleaned his clothes, took care of all of the household responsibilities (bill paying, maintenance, errands, etc.) and, most importantly, she loved him. There came a time in caring for Herman when the family made the decision to move him to a skilled nursing facility. This decision was not easy for anyone, especially Rachel. The hospice team had become concerned about her ability to care for Herman as her own

health and well-being were being compromised. After Herman was moved, Rachel was placed on hospice service as well. Her health had declined and she was simply worn out. Rachel's sense of meaning and purpose had been replaced by depression and heartbreak, because without Herman to care for, Rachel felt she had no reason to live. It became clear in conversations that Rachel felt she had no reason to continue living. Herman was being well cared for and her children were all grown and had lives of their own. Rachel defined herself as more spiritual than religious and seemed at peace with the prospect of her own death now that she deemed there was no reason to continue to live. A few months after Herman was moved to the skilled nursing facility, Rachel developed pneumonia and died within days of the diagnosis.

Charlie

Charlie lived with his daughter and her family, and by the time I met him he was spending all of his time in an upstairs bedroom. Charlie was a man who had been incredibly responsible and had taken good care of his family, providing for all of their needs. He worked hard as the breadwinner and loved his deceased wife greatly. When I met him, Charlie was confined to a hospital bed yet

still attempted to provide for as many of his own needs as he could. His daughter worked a full-time job, and her husband and son were limited in their ability to care for Charlie. During our first visit I discovered that Charlie hadn't eaten since early in the morning. He had a glass of water on a hospital tray table, along with a box of Kleenex, and his Bible. I offered to get him some fresh water and make him something to eat. Even though Charlie told me he didn't want to be a bother, he instructed me in finding all that was necessary to make him a can of soup. The hospice team discussed concerns about Charlie being left alone in this manner, as others had witnessed his inability to care for himself amidst his protests. The next time I visited, Charlie had a small cooler sitting on the tray table. Charlie was beginning to acknowledge the fact that he could no longer care for himself independently. The next step was encouraging Charlie and his family to hire a paid caregiver to assist with Charlie's care. Each step in this process was a struggle for Charlie, as he experienced a loss of his independence and identity with each change. This sense of loss exacerbated another loss for Charlie in the relationship

with his son. Charlie's identity had begun to shift, allowing him the opportunity to reflect on his relationships, and although Charlie would define himself as a person with deep Christian faith, he agonized over the loss of relationship with his only son. We talked about this, and Charlie began to realize that rather than being the caregiver, he was in a position to receive care. This care came in the form of his brother and nephew, who encouraged Charlie to reach out to his son. He did reach out, and the response was overwhelming for him, because his son reached back. They were able to connect in a way they never had before, and Charlie's identity as "father" gave him a great sense of peace.

Mona

When I met Mona, she was living in a small apartment with her son. She had been divorced for some time and had a very strong bond with her only child. Mona's identity had been wrapped up in being the wife of a physician and the mother of a precocious child. When her husband left her for another woman, she felt very betrayed and latched on more tightly to her son. Eddie, her son, had been divorced once and worked from home. It was obvious that even though they loved one another there was tension in the

relationship as well. Eddie was dating, and eventually fell in love again, much to his mother's chagrin. Mona remained angry and hostile about her loss of identity in her relationship to her ex-husband and became angry and anxious about her role in the life of her son. When Mona and Eddie moved to a new home, Eddie's girlfriend moved in with them, which infuriated Mona. She perceived this as another opportunity to be victimized and betrayed, although she received better care and support than she had had before. In our conversations Mona continually expressed her dissatisfaction with every aspect of her life and her disappointment at not being the center of attention anymore. Mona's identity as patient became a role she relished as it garnered her the attention for which she yearned. She remained focused on material things and fearful of delving deeply into spiritual matters. Her anger and frustration spilled into her sense of relationship with the Divine, and Mona remained fearful of dying and what would happen to her soul. Mona's identity as wife and mother was slipping away, and she had nothing to replace it with, including her understanding of herself as a child of God.

Ernie

Ernie was a retired businessman who had spent all of his adult life providing for his family. A diagnosis of advanced cancer of the stomach turned Ernie's world upside down. His family gathered around him to provide for his needs, placing Ernie in a position that was foreign to him. Ernie's wife noticed a change in his behavior as he withdrew from the family and spent more time in introspection. A hospital bed had been set up in a small den where Ernie spent his time watching TV and sleeping. Although he had apparently been experiencing pain for quite some time, Ernie didn't share this information with his family until he became physically ill. After the diagnosis, Ernie's role as provider was no longer valid. This loss of identity caused Ernie to slip into a state of depression from which he never recovered. Even as his family expressed their care and concern for him, Ernie withdrew, causing his family a great deal of sadness and confusion in the midst of their grief.

Many life transitions cause us to reassess aspects of our lives. Rachel, Mona, and Ernie were unable to cope with the major life transitions they were facing. All

three became more isolated because they lacked a sense of meaning and purpose as their realities changed. Charlie, on the other hand, was able to redefine who he was, find new meaning and purpose, and face his life transitions openly. Terminal illness is an especially potent impetus for coming to terms with our sense of value and worth with respect to our relationships and ourselves. When faced with the realities of terminal illness, many individuals are thrown into crisis because of a loss of identity. Adaptability is key in helping us to discover new understandings of ourselves and our relationships.

Our ability to adapt can enhance the process of reconciliation that is needed on every level by an individual with terminal illness. Ira Byock writes about the need for reconciliation in *The Four Things That Matter Most*. He writes that the four things that need to be said are: "Please forgive me," "I forgive you," "Thank you," and "I love you."⁶ These may sound like remarkably simple statements yet their effect is profound. I have encouraged families to use these statements to share with one another the things that have real meaning in their lives. The

⁶ Ira Byock, *The Four Things That Matter Most* (New York: Free Press, 2004), 3.

spiritual work that transpires in these precious moments of sharing is sacred. In the following stories, both Anita and Timmy found it necessary to grapple with their relationships with the divine. They entered into sacred space by being vulnerable and grappling with their hopes and fears.

Anita

Anita was one of those folks for whom the cup is always half full. She was living alone in the home that she shared with her husband for most of their married life. Anita now spent most of her days tethered to her oxygen tank and sitting in a large recliner in her living room. This was where she welcomed visitors and friends to spend time with her and bring some of the world into her home. The first time we met, Anita wanted to know what I thought happens when you die. I asked her what she thought happens and we had a wonderful conversation during which a bond of trust was built. Even though her health continued to diminish and her world had grown smaller, Anita still found incredible joy in the simple things in life. One of her neighbors stopped by every morning to bring his young dog to visit her. I was present during one of these visits and watched as Anita lit up at the antics of this puppy. Here

was a woman who was very aware that her days were numbered, and yet, she found unabashed joy in spending time with an exuberant puppy. Anita talked openly about the fact that it was getting more difficult to breathe and that her mind was not as sharp as it used to be. She cried at times, not out of fear, but out of a sense of sadness at leaving this life even though she believed there was something incredible awaiting her. I admired Anita's courage and openness in facing her impending death. During our visits, we would laugh and cry and talk about things profound and mundane. Anita had said the things that needed be said and done the things that needed to be done, she had offered and received expressions of care and love. Only one thing had troubled her, and that involved a relationship with her former pastor. She had been a very active member of her church and was quite hurt and disillusioned that the pastor didn't call or visit her when she became homebound. Concerns about her funeral and continued pastoral support were dismaying to her until a new neighbor moved in, who happened to be both a nurse and the new pastor of the small congregation nearby. We talked about her concerns, and I encouraged her to welcome her neighbor's offers of support.

After her conversation with him, Anita felt reconciled and reconnected to a community of faith and was able to put to rest her concerns about her funeral. This enabled Anita to have a conversation with her son that she had been avoiding because she feared causing him pain. Anita and her son Dennis were able to sit down and talk about how much they loved one another and what their expectations for the future were, especially regarding Anita's funeral. Anita told me that after speaking with her son and her new pastor she felt at peace about what the future held for her.

Timmy

Timmy's living situation was one that could be described as less than ideal. He lived in a rather decrepit mobile home out in the middle of a dry and arid nowhere with some relatives. Timmy had walked on the hard side of life and now the reality of dying created concerns about what would be next. His nurse had forged a bond with Timmy, who was very honest and somewhat ashamed of the life he had lived. This team member encouraged Timmy to talk with a spiritual care provider, even as he expressed concern about being judged by others, especially "someone with a direct line to God." The nurse continued to build the relationship and developed a trust that enabled Timmy

to agree to talk to me. After conferencing with the nurse, she and I visited Timmy together and he admitted his anxiety in meeting me. I saw what the nurse saw: an emaciated, worn out, slumped over body housing a very lively spirit. He was very direct in expressing his concerns to me regarding my possible assumptions about him. As we listened, both the nurse and I were aware that Timmy needed reassurance that he was acceptable to us and especially to God. During the ensuing visits with Timmy, we spent time with him as he grappled with questions about his disease process, particularly about his perceptions and concerns regarding heaven and hell. After building our relationship, the nurse and I brought communion to Timmy. He had been a non-practicing Catholic for many years and was surprised that we would celebrate communion with him. During our prayers, Timmy took the opportunity to seek forgiveness from God and received an assurance of pardon. He found great comfort in this sacramental act and opened up more about his concerns about death and dying. Timmy's remaining days were a bit hellish, considering his living arrangements, yet he was able to find a sense of internal peace that had eluded him for many, many years.

Anita and Timmy risked trusting in their sacred relationships and both found a new sense of fulfillment and peace as a result of their faith and their actions.

Spiritual care offers us the opportunity to be fully present with one another. It enables us to be aware of, and care for, the whole human being – body, mind, and spirit. The opportunities for providing spiritual care are as diverse as the relationships we build with one another. An essential aspect of spiritual care is building relationship. One of the most important skills is the ability to listen and really hear what is being said on every level. Someone may tell you that they feel fine, yet you can tell by the skin tone, facial expressions, and food left uneaten that they really are not fine. Spiritual care implies listening as fully as possible with all of our senses and with our own spirits.

According to the *Guidelines for Spiritual Care* published by the National Hospice and Palliative Care Organization, the Principles of Spiritual Care include the following:

- At the heart of spirituality is the universal human capacity for transcendence, that is, the awareness that we humans, individually and collectively, are part of a spiritual reality greater than ourselves.

- As for the relationship between spirituality and religion: The relationship is of the whole to the part; religion is spiritual but not all spirituality is religious. They are not synonymous terms. Spirituality, the larger reality, may be expressed explicitly or tacitly in traditional religio-cultural terms, in non-traditional religious terms and or in humanistic terms. Thus spiritual care considerations are appropriate even when patients and families identify little or no interest in religion.
- As for the spiritual care relationships on the hospice interdisciplinary team: spiritual care attends to fundamental issues of existentially transcendent awareness, relatedness, meaning, purpose, and wholeness. The spiritual perspective may come, as it often does, from any person on the team.
- In hospice, spiritual care accepts, affirms, and respects authentically expressed diverse belief systems and spiritual practices. This principle applies to both the hospice staff involved and the "primary unit of care," the patient and family.
- In hospice, the needs and goals of the patient and family are central to the planning and provision of spiritual care.⁷

What these principles share is an understanding of the complexity of spirituality and of spiritual care. These guidelines offer validation of the need for specialization in spiritual care in hospice - care provided by those with the appropriate education, training, and experience. They also offer a good foundation for the understanding of

⁷ National Hospice and Palliative Care Organization, *Guidelines for Spiritual Care in Hospice* (Alexandria, VA: National Hospice and Palliative Care Organization, 2001), 4.

spiritual care as it is meant to be practiced in hospice philosophy. A model for spiritual care would enhance the practice of the discipline in the hospice setting.

As part of the practice of spiritual care I encourage my colleagues to connect with their own senses of spirituality. We share experiences and stories which remind us all of the spiritual qualities of the dying process. These experiences offer opportunities for us to honor our spirituality and for all of us to be more fully present with one another. While the clinical aspects of the dying process are reviewed with regularity, it is the spiritual aspects which have the most profound and lasting effects on my hospice colleagues and me.

CHAPTER 3

THE VOICES OF OTHER HOSPICE DISCIPLINES
REGARDING SPIRITUAL CARE

Treat no one lightly and think nothing useless, for everyone has a moment and everything has its place.

- Ben Azzai, second-century Jewish sage¹

As my hospice colleagues and I work to provide the very best end-of-life care possible, I have come to truly appreciate being part of a collaborative team in these endeavors. Working together allows us to build off of each other's strengths, support one another, and respect the unique contributions we each bring to our provision of care for patients, families, and one another. There is a great deal of research being done in the medical field regarding spirituality and its effects on everything from healing to dying peacefully. This choir of many voices is examining spirituality from many facets and underscores the need for acknowledgement of the spiritual components of human existence.

I have had the opportunity to work with many talented and gifted individuals on several hospice teams. One of my

¹ Quoted in Brussat, 433.

home health aide colleagues was known for being present at the time of many patients' deaths. We even learned of instances where patients seemed to wait for her to be with them and would die while she was present. I asked her about her experiences with the dying and she told me very simply that her job was to take care of our patients and to love them. Her touch and voice were gentle and compassionate and her singing was soothing. I watched her with patients on several occasions and noticed that people seemed more relaxed as she spent time tending to their needs. Her way of being present was deeply spiritual.

Having a conversation about what defines spiritual care, and who provides such care, is essential. It is also important to examine who has been involved in the dialogue thus far. Nurses and social workers have completed a great deal of the existing writing concerning spiritual care in a hospice setting. These two clinical disciplines have offered interesting perspectives on spiritual care in both study and practice.

An article in the *American Journal of Hospice and Palliative Care* entitled "A Systematic Review on Chaplains and Community-Based Clergy in Three Palliative Care

Journals: 1990-1999" highlights the types of articles regarding spiritual care published in a specific decade, delineating between research and non research, qualitative and quantitative, and mention or exclusion of clergy/chaplains in some way.² This article and "Pastoral Care, Spirituality, and Religion in Palliative Care Journals,"³ show the complexity of the deliberations on spiritual care and spiritual care providers in a hospice setting. The second article reviews the topics of pastoral care, spirituality, and religion appearing in twelve professional palliative care journals between January 1984 and January 2002.

It is interesting that this conversation about spiritual care has included nursing and social workers has validated their own professions as facilitators of spiritual care and virtually ignored ordained clergy with specialized training as essential conversation partners. So, an important question begs exploration at this point -

² Kevin J. Flannelly et al., "A Systematic Review on Chaplains and Community-Based Clergy in Thee Palliative Care Journals: 1990-1999," *American Journal of Hospice and Palliative Care* 20, no. 4 (2003): 263-68.

³ Maaike A. Hermensen and Henk A.M.J. ten Have, "Pastoral Care, Spirituality, and Religion in Palliative Care Journals," *American Journal of Hospice and Palliative Care* 21, no. 4 (2003): 353-56.

does spiritual care in a hospice setting merit professional practice, and if so, by whom? In order to respond, it is necessary to gain an understanding of the training required in the disciplines of nursing, social work and spiritual care and to determine the scope of practice of spiritual care in hospice.

According to the California Employment Development Department website:

registered nurses must be licensed to practice in California by the State Board of Registered Nursing. The license requirements are: Completion of a board-approved nursing program. A passing grade on the State Board examination.

Two types of Registered Nurse training programs are available in California: two-year community college associate degree programs and four-year bachelor's degree programs. Both programs include clinical experience in one or more hospitals and clinics in addition to classroom instruction. Most community colleges give Licensed Vocational Nurses (LVN) credit for their basic nursing course work and experience. LVNs can complete the requirements for an associate degree in nursing in two years. At that point, a LVN can work or transfer to a four-year college to obtain a bachelor's degree in nursing to be licensed as a RN. LVNs with associate degrees, or former military medical corps workers, may qualify for advanced placement in four-year bachelor's degree nursing programs. There are currently 22 schools that offer a baccalaureate degree in nursing, and over 70 schools in California that offer two-year degrees in nursing.⁴

⁴ California, "Nurse Practitioners and Registered Nurses," California Occupational Guides, no. 29 (2002). [online]; accessed 20

In addition to a registered nursing license, some hospice nurses gain additional training and certification in palliative care. The Hospice and Palliative Nurses Foundation promotes research and education of nurses with the belief that "nurses are central in providing compassionate and quality care for people facing life-limiting and terminal illness".⁵ Along with its sister organization, Hospice and Palliative Nurses Foundation, it promotes nursing as the core and most critical profession in end of life care. Much of the nursing literature espouses that "with their knowledge about the physical, psychosocial and spiritual dimensions of life limiting and terminal illness, nurses are central in assuring the comfort, autonomy, and healing of patients and families".⁶ The academic education of most hospice nursing staff requires a two-year degree in nursing from a community

Aug. 2005; available at
<http://www.labormarketinfo.edd.ca.gov/cgi/career/?PageID=3&SubID=140#N>.

⁵ Hospice and Palliative Nurses Association, "Hospice and Palliative Care Nurses Foundation Home Page," accessed 20 Aug. 2005; available at http://www.hpna.org/HPNF_Home.asp.

⁶Barbara Cliff, et al., "Position Statement - Value of Professional Nurse in End of Life Care," Hospice and Palliative Nurses Association [online], accessed 20 Aug. 2005; available at http://www.hpna.org/pdf/PositionStatement_ValueOfProfessionalNurse.pdf.

college and licensing in order to be a registered nurse. The experiential training of hospice nurses varies greatly, with some having just graduated and been licensed.

Social work requirements for hospice care vary according to the needs of the hospice. The range includes social workers with associate and bachelor degrees in social work, social workers with masters degrees, and licensed clinical social workers with masters degrees. Experience also factors into eligibility and those in supervisory positions are normally required to have a state license and experience in the field of health care.

Spiritual care can be observed as following the same need for specialization. The scope of practice includes those with the following academic training: no formal theological education; bachelor degrees in religion or theology; master of divinity degrees, master of theology degrees; doctoral degrees; and clinical pastoral education. Some hospices use local clergy to provide care on an as needed basis (paid and volunteer) and others have mandates to employ staff with graduate level degrees and clinical experience. Most states do not have a licensing mandate for spiritual care providers at this time.

Spiritual care, nursing, and social work offer a spectrum of requirements for those practicing the disciplines in hospice and palliative care. As hospice and palliative care become more refined and defined, more requirements of specialization are placed on the disciplines involved. At most hospices, all disciplines are encouraged to engage in continuing education, and some disciplines have particular amounts of continuing education required to maintain licensure and certification. Specialized credentials are also encouraged, and incentives may be offered to those who receive them, including tuition reimbursement.

The interdisciplinary construct used in hospice allows for an intertwining of the aspects of care provided by the different team members. It also permits diversity within the team that can enhance the individualized care for the patient and family. Even though team members have distinct roles and training, there can be a blurring of boundaries into one another's disciplines. A home health aide may pray and sing hymns with a patient while bathing him or her (providing spiritual care). A social worker may encourage a spouse to give a medication according to its frequency

for pain relief (providing nursing care). A spiritual care provider may encourage the family to select a funeral home or consider the additional support of a volunteer (providing social services). A nurse may change a bed or cook a meal (home health care). A look at some living human documents may make this type of interaction more clearly understood.

Alice

Alice was a middle-aged woman who was dying from breast cancer that had metastasized to her brain. Although loving family members surrounded her, it was very difficult for them to deal with the reality that their loved one was no longer able to interact with them. Alice was no longer able to talk and could not move on her own, even as she lay there with her eyes open. She seemed to respond to her family's "I love you" statements by blinking. The home health aide assigned to Alice had been involved with her care for several weeks and had established a relationship with both the patient and the family. The family was having an extremely difficult time watching the decline of their young matriarch and felt helpless in their desire to care for her. The home health aide (HHA) spent time lovingly bathing Alice and changing her clothes and

bedding. During these interactions the family could see and hear the aide at work. Singing and prayer were part of the interaction between caregiver and patient. The HHA provided a spiritual presence as she cared for the patient and the family acknowledged that Alice appeared more peaceful when the HHA left.

Fred

Fred was a man in his early eighties who lived with his wife in a retirement community. They had grown children who lived in other parts of the country and depended greatly on each other for support. Fred had been married for over sixty years to his high school sweetheart and had always taken care of her. Now that Fred was dying, she felt overwhelmed. The nurse had taken a pill minder to the home and filled it with Fred's medications that were in pill form. His wife was to give the medication according to the prescriptions, and using the pill minder made this task simpler. She was also supposed to give Fred some liquid pain medicine when needed. A social worker was visiting Fred to assist with the processing of some documents when she noticed Fred was grimacing and agitated. After asking if Fred was in pain and getting an affirmative response, the social worker asked when Fred had last been

given pain medication. Fred's wife stated that she had given him some the night before. The social worker spoke with the couple, reminding them of what the nurse had told them about the pain medication. In talking with the couple, the social worker discovered that Fred's wife was anxious about giving the liquid pain medication because she was afraid it would hasten his death. After some reassurance and re-education offered by the social worker, Fred's wife gave him the pain medication and felt more comfortable in doing so. Fred's pain was eradicated and his quality of life enhanced because of this social worker's intervention.

Marvin

Marvin, a man in his late seventies, had been married to his second wife and current spouse for twenty-three years. They had both been married before and were enjoying their retirement together when he was diagnosed with end stage congestive heart failure. Upon admission to hospice, they had been asked to consider and make decisions about several things, including the "do not resuscitate" order (DNR) and final arrangements for burial or cremation. Even as Marvin grew weaker, his spouse was reticent in making these important decisions. The spiritual care provider

visited and discovered that these decisions had not been made because the couple was unsure about what to do. They both had burial plots elsewhere, yet really wanted to stay together. The spiritual care provider listened to their concerns and encouraged them to make their wishes known to family and to honor them for one another. After some honest discussion, Marvin and his spouse decided to be cremated and Marvin wanted his ashes sprinkled at the beach and on the golf course, two of his favorite places. Once they were open to this aspect of the conversation, it made it much easier for them to sign the DNR and pick a mortuary to handle Marvin's final arrangements. The spiritual care provider was able to support them in discussing their final wishes in a loving and honest manner.

Estella

Estella was a woman in her early seventies living in a small home with her disabled adult son. Estella was suffering from degenerative heart disease and was unable to care for her son or herself. The house was a mess and no one could determine the last time Estella had bathed. She had great difficulty in getting around and the smallest exertion wore her out. Her son was paralyzed and bed bound and had been dependent on his mother's care. When the

nurse arrived and assessed the situation, a home health aide was assigned to the patient. The patient refused to accept the assistance of a HHA and the nurse stepped in and worked at building trust as she slowly cleaned Estella's house and cooked for her. As Estella's trust level increased, the nurse was able to recruit more assistance, including a HHA and a paid caregiver to assist with the activities of daily living. Estella had no insurance and was anxious about her son's welfare. The nurse worked with the rest of the team to provide for the needs of Estella and find support resources for her son.

Each of these hospice patients received care in a holistic and compassionate manner from team members who were able to adapt to particular situations and support one another in providing the best care possible. One of the most essential components in working as a team is communication. In each of these cases team members were in communication with one another, giving and receiving guidance and support.

As demonstrated, the hospice team approach works well because there is some interplay between the different disciplines as they strive to provide quality care to every

patient and family. Yet as there is an intertwining of the disciplines in providing care, there remain clear distinctions regarding the mandates for care provided by the core team disciplines. Many of the nursing and social work contributions to the discussion of spiritual care in a hospice setting allocate their respective disciplines as the purveyors of spiritual care.

In an article entitled "The Spiritual Care Perspectives and Practices of Hospice Nurses," Belcher and Griffiths write:

Spirituality and spiritual care are acknowledged as essential aspects of quality patient care...There also is considerable debate about who assumes primary responsibility for initiating or coordinating spiritual care. In many instances, spiritual assessment is not conducted and, when it is, the resultant diagnosis and planned interventions are frequently not adequate to meet the spiritual needs of the patients...that nursing staff do not have the necessary skills and competencies to meet their patients' spiritual needs.

It is evident from the data that hospice nurses, in contrast to nurses in other practice settings, have a heightened sense of personal spirituality, and value the integration of spiritual care into their practice...Personal spirituality and a knowledge base to support spiritual caregiving were significant factors in hospice nursing staff members' competence and confidence in providing this intimate level of care...However, the respondents also said that they were committed to integrating spiritual care at a higher level and with a greater degree of sensitivity to the diversity often expressed by hospice patients and their families. Consequently, they look for an

enhanced knowledge base and identified a wide range of topics and areas in which expertise should be augmented.⁷

What is being said is that while spiritual care is an essential aspect of quality patient care, nursing staff do not have the skills and training to meet the spiritual needs of patients. Several nurses' groups, including the Hospice and Palliative Nurses Association continue to assert that spiritual care can fall under the responsibilities of the hospice nurse rather than that of the spiritual care provider. The organization's position statement acknowledges the crucial need for spiritual care yet considers chaplaincy an additional resource.⁸

Likewise, the field of social work continues to press for validation of social workers to provide spiritual care. In "Educational Needs of Hospice Social Workers: Spiritual Assessment and Interventions with Diverse Populations," Wesley, Tunney, and Duncan write:

Spiritual care is a growing function of social workers who work with terminal patients, their families, and their friends. Traditionally, clergy

⁷ Anne Belcher and Margaret Griffiths, "The Spiritual Care Perspectives and Practices of Hospice Nurses," *Journal of Hospice and Palliative Nursing* 7, no. 5 (2005): 271-79.

⁸ Elaine Glass, Bonnie Meyer, and Donna Morely, "HPNA Position Statement - Spiritual Care," [online]; Hospice and Palliative Nurses Association, accessed 15 Nov. 2007, available at http://www.hpna.org/pdf/PositionStatement_SpiritualCare.pdf ., 2.

were considered responsible for spiritual care. However, all other caregivers, including social workers can provide spiritual care to the dying. Although the Joint Commission on Accreditation of Healthcare Organizations mandates spiritual assessments in its standards, and the National Hospice and Palliative Care Organization (NHPCO) supports interdisciplinary spiritual care, neither organization provides specific guidelines for social workers.

Important lessons for social work practice and education include helping social workers reflect on and resolve role conflicts and ambiguities through frank discussions during agency inservices and staff meetings. Access to recent literature in social work can help practitioners and students understand the contemporary professional view of the role of social workers in spiritual care. Discussions among practitioners and students should address role conflict issues explicitly. In addition, agency policy should address role division as a reflection of the hospice organization's mission and philosophy.⁹

In other words, social work professionals, like their nursing counterparts, feel that spiritual care can be provided for by their discipline, with little regard for the necessary academic and experiential training required by professional chaplaincy or the specialty of spiritual care with the dying.

Traditionally, spiritual care of the dying has fallen under the auspices of spiritual care providers (clergy, priests, nuns, community spiritual leaders) and the hospice

⁹ Carol Wesley, Kathleen Tunney, and Ella Duncan, "Educational Needs of Hospice Social Workers: Spiritual Assessment and Interventions with Diverse Populations," *American Journal of Hospice and Palliative Care* 21, no. 1 (2004): 40-46.

movement has been grounded in spiritual care as evidenced in Chapter 1.

The hospice movement...is firmly rooted in reality. The facts of human life are its base: physical facts, psychological facts, historical facts, economic facts, and not least of all, the fact that spiritual forces are at work in us constantly, however little we may be aware of them. The hospice process, whatever its location, its staffing and funding problems, or the stage of development reached by a particular facility, is faith in action. Humanists may prefer to call it faith in humanity; atheists may insist that it has nothing to do with God; and many people within the movement itself are willing to work for the comfort of the dying without believing in any sort of afterlife. Nevertheless, faith is the heart of this process and this profession, simply because there is no other force (by whatever name) that could cause people to behave toward one another as they do in the hospice situation. Physical care of those who are "failing" can be bought and paid for. "Useless" members of society can be dealt with by legislation, revolution, or simple elimination. The energy for hospice work, however, must come from an entirely different source.¹⁰

Stoddard's writings assert the validity of the need for professional chaplains/spiritual care providers in a hospice setting. As the hospice movement increases its dependence on professionally trained team members, more hospices are requiring that spiritual care providers meet a minimum set of standards. These standards include: an undergraduate degree from an accredited college or university, a Master of Divinity degree from an accredited

¹⁰ Stoddard, 195.

institution, Clinical Pastoral Education training, ecclesial endorsement to practice specialized ministry, and internship/residency in specialized areas of ministry. The course work for a Master of Divinity degree requires a minimum of 72 hours in the fields of theology, church history, world religions, pastoral care, ethics, religious education, preaching, polity, research languages (Greek, Hebrew, French, German, etc.), and practical ministry.

The need for effective spiritual care is made evident using another living human document. This case study reflects the need for both education and skill in the areas of theology and psychology in order to meet the patient and family where they are.

Maxine

Maxine was a woman in her late seventies who lived with her extended family. Her entire life had been focused on caring for others - her spouse until his death, her children and her grandchildren. She was also very involved in volunteer work at the local hospice. Maxine was diagnosed with terminal cancer and was put on hospice service when the cancer metastasized to her liver and bones. This was a woman with a strong sense of faith who talked about her spiritual journey and who reassured others

that she was at peace with her impending death. Maxine and her family received visits from many of her friends and colleagues at the hospice and she relished the attention and care. She began to give away her belongings and say goodbye to those who visited. As she grew weaker, Maxine appeared more withdrawn. As team members attended to her care, she always inquired about them and their well-being. A spiritual care provider spent some time with Maxine and they prayed together. A eucharistic minister brought communion. Still, something did not seem settled in Maxine - she was not at peace. A spiritual care provider listened as Maxine expressed concerns about being a good enough wife and mother and whether or not she had done enough with her life. Translating from psychological insight to theological insight, the spiritual care provider asked Maxine if she had concerns about being good enough to receive God's love and grace. Maxine was silent as tears fell down her cheeks. She had always tried to do and be the best she could. The spiritual care provider reminded Maxine of God's unconditional love for her and expressed appreciation for knowing such a good and faithful servant. The confusion left Maxine's eyes and a new sense of peace

appeared there. As they prayed together, both were reminded of how blessed they were by the grace and love that bound them together and to God.

The language that is used by patients and families may have layered meanings. In Maxine's case the underlying concern was about being "good enough" for God, not her family, as death approached. Translating from one specialized language (psychology) to another (theology) requires a great deal of training and experience. One must understand the construct of the linguistics of both fields as well as their frameworks. Effective spiritual care requires a commitment to discern a person's reality on every level - body, mind, and spirit. Theology is defined as the study of God (the divine), and this study of relationship to the divine/spirit must be taken as seriously as the study of the human body or the human mind. Hospice practitioners expect nurses and social workers to be as thoroughly trained and as competent in their disciplines as possible. It is necessary that the same training and competency be required of those providing spiritual care. Respect for and support of these specialized disciplines can only result in enhancing the

quality of care provided for patients and families. Spiritual care of the dying requires and deep understanding of what spirituality is, how essential a spirituality of dying is to those in the process of dying, and the ability to comprehend the diverse manifestations of spirituality claimed by patients and their families. Hospice nurses and social workers do not have the training or expertise to stand in truly spiritual space with patients grappling with the spiritual process of dying. Professional spiritual care providers do.

All of the members of the hospice team may have a sense of spirituality that underlies the way they approach the work that they do. My colleagues from every discipline have much to offer from that perspective and our patients and families benefit greatly. It is also important that the knowledge and experience of those who are intentionally and specifically trained to provide spiritual care have our voices heard in the continued defining and refining of spiritual care in a hospice setting.

CHAPTER 4

DYING

*There is only one law in the universe that never changes -
that all things change,
and that all things are impermanent.
-- Sogyal Rinpoche¹*

People tell my colleagues and me that they do not understand how we can do what we do. These people focus on their perceptions of one moment in time — the death. Our journey with a patient and family is a process which includes the time of death, yet it encompasses so much more. Our work emphasizes the quality of life and our hope is that patients will die peacefully. We understand the awesome nature of the work we do and the privilege we are given in doing it. Being welcomed into the sacred space is a very serious responsibility and we work to truly honor the lives of our patients and families. One of the aspects of living well is dying well and individuals have their own ideas about what dying well will entail. Our responsibility is to honor individuals' rights to live and die according to their wishes. This is not always easy or

¹ Sogyal, *Tibetan Book of Living and Dying*, 29.

even possible. Many people wish to die at home yet the families are not comfortable with that prospect. Education and experience can help ease family members anxiety and fear. Physical pain may be difficult to manage because of the disease process and medication issues. Some individuals and families will not admit to the reality of the dying process which may be their way of coping with the inevitable.

The process of dying is experienced on physical, psychosocial, and spiritual levels. Observations of death and dying encompass the physiological, psychological, and theological that are explored in this chapter. The dying process discussed here results from terminal illness and not trauma, although it is possible that some of the characteristics are the same.

Dying, from a physiological standpoint, is inevitable. The body shuts down and life is terminated. How does it happen? How do we know someone is dead? These are but two of the questions humans ask themselves when confronted with the reality of impending death. When a patient dies on hospice service, every attempt is made to ensure that the individual has as little pain as possible in the dying

process. Opioids may be used to alleviate any physical pain or terminal agitation that might occur. Although people are placed on hospice because death may occur soon, the term "actively dying" is used when someone actually begins to exhibit signs that physical death is imminent - usually within twenty-four to forty-eight hours.

The signs of active dying include coolness and mottling of the extremities, fever, increased sleeping, decrease in urinary output, decrease in consumption of liquids and solids, restlessness, confusion, congestion, incontinence, and changes in breathing patterns. As the body shuts down there may be an increased sense of agitation on the part of the patient, followed by calm as breathing slows. Death occurs when all vital functions in the physical body have ceased.

A cooling and mottling of the extremities may appear while the patient is still conscious to some degree. This process starts in the hands and feet as the blood flow to those areas is curtailed. Even as body temperature falls in these areas, it is common for a patient to become feverish and clammy around the head and torso. Body temperature may fluctuate as internal organs shut down. Patients sleep

more and become less conscious as the process of dying continues. They no longer need sustenance and desire/require little or no liquid or solid nutrients, resulting in a decrease in urinary output as the kidneys shut down. As patients' muscles relax, the ability to control continence is lost, and confusion and loss of consciousness may occur. Congestion results from a build up of fluids, causing gurgling sounds to come from the chest as though marbles were rolling around inside. These sounds may become very loud and are due to the decrease of fluid intake and an inability to cough up normal secretions. Restlessness results from the decrease in oxygen circulation to the brain and metabolic changes. Respiration fluctuates as organs shut down and a particular pattern of breathing called Cheyne-Stokes breathing will occur. It consists of irregular breathing, where shallow breaths are taken with periods of no breathing for five to thirty seconds that may last a full minute. Rapid shallow breathing may also occur. When breathing stops, and no pulse, heart rate, or blood pressure can be detected, a terminally ill patient may be declared dead.

Hospice staff work with families to keep their loved ones as comfortable as possible through the entire dying process. Families are instructed about what to expect and how to respond to the physiological aspects of dying and are encouraged to consult with staff as needed. Medication may be used to alleviate symptoms, and alternative therapies such as healing touch may also be implemented. Family members are encouraged to continue interacting with patients in gentle, loving ways: talking with them, holding their hands, stroking their foreheads, playing music quietly, keeping them clean and dry, keeping their mouths clean and moist, and remembering that they can hear even if they cannot respond.

Being physically comfortable and surrounded by loved ones allows individuals to die peacefully. As I have witnessed the dying process of many people, I have contemplated what happens when we die. Patients ask. Families ask. I wonder if we don't all ask at some point, "Is that all there is?"

This question has echoed in my head on numerous occasions, particularly when serving as a spiritual care provider with those who were dying or grieving the loss of

loved ones. People are desperately seeking answers to that great mystery that lies in store for each of us, turning to "a person of God" - at the very least seeking solace, and perhaps needing affirmation that death is merely transitional, that something exists beyond our limited imaginings.

In pondering the questions that folks ask about death and the afterlife, about the purpose and the meaning of existence, where does the spiritual caregiver turn? Even after patients have died, and families have been comforted, the caregiver is left alone to wonder, "Is that all there is?"

Christian Theology and the Question of Immortality

Christian theology does not offer a great deal in respect to death and dying. It focuses on life, death, and resurrection as a means for providing understanding of what happens when we die. Jesus of Nazareth, Lazarus, and the daughter of Jairus were all resurrected, raised from the dead, with two of them continuing in this life. While Christian theology can provide comfort with perceptions of an afterlife, it does not grapple with fundamental

questions in deep, meaningful ways. Perhaps that is where the Christian concept of faith in Jesus as the Christ, the fulfillment of God's promises to humanity, is relied upon.

There are many Christian traditions and thoughts about what happens when we die; while they have common basic premises, they vary greatly in individual interpretation. Many of the patients I have journeyed with through the dying process have self-defined as Christian. Their journeys and theologies have been quite diverse. Some find comfort in their concepts of heaven. When asked what they think will happen when they die, most respond with some conversation regarding heaven. Their descriptions vary and include visions of pearly gates and clouds, meeting Jesus, having a healthy body again, seeing loved ones, or knowing a sense of everlasting peace. Others are more concerned about getting to heaven and not going to hell. Many spiritual care providers spend hours providing comfort and reassurance about God's love and grace when patients and families are fraught with fear because of their theological understandings. The Christian concepts of heaven and hell can create a great deal of anxiety in those who are dying. Many of these folks have never pondered these theological

questions very deeply and are caught off guard when death is staring them in the face. Being intentional in asking questions, living by faith, and working through unfinished business help many professing a Christian faith to live fully to the end and die well, finding comfort in their concepts of a loving God and a blissful hereafter.

Process Theology, Buddhism and the Question of Immortality

I believe that Process Theology and Tibetan Buddhism offer possibilities for delving deeper into questions of dying and living. They attempt to respond to the issue of immortality. Webster's Dictionary defines immortality as: "the quality or state of being immortal: a: unending existence; b: lasting fame."² A working definition for this study includes the understanding that immortality connotes unending existence. How the unending existence is experienced may remain a mystery, yet the possibility for it needs to be included in a process model. Whitehead's philosophy is "entirely neutral on the question of

² Merriam-Webster Online, s.v. "Immortality," 2005 ed.; accessed 20 Aug. 2005; available from <http://www.Merriam-Webster.com>.

immortality".³ For a process model to have relevance to those who profess Christian faith (or spiritual faith), it is necessary for the model to address the issue of immortality. For spiritual care providers who journey with those in the last stages of life, it is essential to seek some deeper understanding of process theology. Grappling for deeper understanding and meaning is at the core of the spiritual journey.

Jennie

Jennie was eighty years old when she decided to terminate dialysis treatments, and ultimately, her life. Because they could not cope with her decision, Jennie's family abandoned her. She had not cultivated friendly relationships with anyone in the skilled nursing facility where she lived, so Jennie was left to ponder her decision, and the outcome, alone. I had begun to work at the facility and Jennie asked to speak with me. We began a relationship that spanned several weeks - the rest of Jennie's life. I had the privilege of becoming Jennie's family during that time and together we prepared for

³ Alfred North Whitehead, *Religion in the Making* (New York: Fordham University Press, 1996), 107.

Jennie's death. Jennie kept asking if she'd done the right thing, particularly because her family was so unaccepting. She answered her own question in the affirmative, confessing at one point that she didn't realize "it (dying) would happen so fast." I spent several nights sitting by Jennie's bedside, knowing that nighttime was the hardest - being left alone in the dark with nothing for company but the contemplation of imminent death. The night before she died, Jennie experienced a visit from her deceased sister, bringing medicine to make Jennie feel better. Jennie was incredibly happy and surprised to see this sister whom she loved so much. The following night, Jennie died as I held her hand. Jennie's struggle was over. My struggle continued - "Is that all there is?"

What happened to Jennie as the life drained out of her physical being? In terms of process metaphysics, was she no longer able to maintain a physical pole, a feeling of otherness, and thereby no longer able to exist? Was it possible that the complexity of actual entities that constituted Jennie continued in some energy form, even if she no longer lived?

Being an active participant in Jennie's dying process allowed me to reflect upon this question and how it is formulated. I propose that we always live in the subjective when dancing so closely with death. We are affected by our grief, by stress, by our sense of the spiritual, and by theoretical problems and questions.

Imagine a diagram comprised of four concentric circles, like a bulls eye. Each of the concentric circles represents an aspect of the effect the dance with death has upon the survivor. The center-most circle represents the reality of the death and our acknowledgment of that reality — grief. The second circle represents the stress that is related to being actively involved in this process. It is stressful to witness a death no matter how peaceful the death is. The third circle represents our sense of the spiritual in relation to death and to ourselves. Finally, the fourth circle represents the theoretical problems and questions that arise when pondering the unknown aspects of death and dying. (This dissertation is an example of grappling with these problems and questions.) All of these layers evolve in response to the reality of a death and its effects upon the survivor(s). Seeking understanding

encourages us to continue to question the unknown, to continue to be in process.

Even Whitehead's work in process thought was continually in process. Process theologians who consider his work as foundational continue to seek greater understanding of creation and the divine. In *Physics and Whitehead: Quantum, Process, and Experience*, Philip Clayton cites three tenets as a means for summarizing Whitehead's metaphysics:

1. Experiential units, constitutive of both processes and objects are basic elements of reality.
2. Time is not an incidental aspect of reality, added on to fundamentally static things; instead, temporal change is a fundamental feature of the physical world itself. The switch in relativity theory to space-time means that time is not just an index of change for things, which really exist only as three-dimensional objects. Duration thus becomes an intrinsically spatiotemporal notion.
3. Objects should not be taken in isolation, defined on their own, and then considered in their relations to other objects. Instead, relations are primary, and objects are defined in terms of the network of relations of which they are part - relations between other parts of the physical world, between other temporal instances present and past, and perhaps between nonphysical moments as well. Ultimately, the entire physical cosmos

represents a single system in terms of which individual objects are to be defined.⁴

In pondering these questions, it is important to consider how/if other feminists are approaching the question of immortality in a Process Theology model. In *The Journey is Home*, Nelle Morton's appendix is entitled "Journal Jottings". In it section she demarcates a beginning point for "Questing the Quest." These are among her jottings:

Gertrude Stein opened her eyes and asked family and friends gathered about her bed, "What is the answer?" A deep breath followed her closing eyes. Then she lifted her head and asked, "But, what is the question?" In the stunned silence of her waiting family she died.

What is the question?

Rainer Maria Rilke is often quoted as admonishing us to stay by the question and then perhaps in some future the answer will come.

Always there are questions posed directly to Faith out of Faith. These become sharper and sharper until at the very end they become addressed to the bare core of Faith itself.⁵

What is the question? "Is that all there is?" If existing as a complexity of actual entities enables us to have human form and self-consciousness, is there

⁴ Philip Clayton, "Introduction to Process Thought," in *Physics and Whitehead: Quantum, Process, and Experience*, ed. Timothy E. Eastman and Hank Keeton (New York: SUNY Press, 2004), 6-7.

⁵ Nellie Morton, *The Journey is Home* (Boston: Beacon Press, 1985), 221.

intentionality about the increasing complexity of our existence? In "staying by the question," one might contemplate the reality that, metaphysically, we are complex forms of energy, created from the same material that makes up the cosmos, and ultimately, God. If this is so, what happens to the energy that is intentionally us, upon the demise of the physical body?

Rosemary Radford Ruether's writings concerning immortality are challenging. She posits that:

All the component parts of matter/energy that coalesced to make up our individuated self are not lost. Rather, they change their form and become food for new beings to arise from our bones. To bury ourselves in steel coffins, so that we cannot disintegrate into the earth, is to refuse to accept this process of entering back into the matrix of renewed life. ...But what of the meaning in our lives; what of the good to be remembered and the evil redressed? Is this merely the matrix of all? ...That great collective personhood is the Holy Being in which our achievements and failures are gathered up, assimilated into the fabric of being, and carried forward into new possibilities.⁶

An ecofeminist, Ruether's priority appears to be establishing a theology that will call humanity to live fully as a part of creation. This ecofeminist theology focuses on humanity's place in creation, in the Matrix.

⁶ Rosemary Radford Ruether, *Sexism and God-Talk: Toward a Feminist Theology* (Boston: Beacon Press, 1983), 258.

Apparently Ruether's position of objective immortality is one that adjudicates that the human life form is ultimately fodder for the sustenance of other life forms that succeed it. Granted, the physical body may deteriorate and serve creation in such a manner, thereby nourishing other physical entities. What about the energy that exists as a soul/spirit? Whitehead's image of immortality in God was created with the concept of soul in mind.

An enduring personality in the temporal world is a route of occasions in which the successors with some peculiar completeness sum up their predecessors. The correlate fact in God's nature is an even more complete unity of life in a chain of elements for which succession does not mean loss of immediate union. This element in God's nature inherits from the temporal counterpart according to the same principles that by which in the temporal world the future inherits from the past. Thus in the sense which the present occasion is the person now, and yet with his own past, so the counterpart in God is that person in God.⁷

Even though Ruether and Whitehead both skirt the issue, perhaps appealing to a sense of objective immortality, it is curious that neither is willing/able to stay with the tension/ambiguity which results when contemplating the immortality of the soul. Ruether is

⁷ Alfred North Whitehead, *Process and Reality*, ed. David Ray Griffin and Donald W. Sherburne, corrected ed. (New York: Free Press, 1978), 531-32.

focused on the survival/coexistence of all creation, which leads to a new ethic for living as humanity and participating in the healing of the earth. She places priority on this radical justice issue and is primarily interested in delineating humanity's response to this call for transformation.

Whitehead's focus appears to be on understanding the concept of God in his process model. Initial aims originate in God, creating a new occasion. An occasion, existing in the present, incorporates within itself its past, a past which influences God's consequent nature. Because an occasion, human, can influence the consequent nature of God, Whitehead states that that person is in God. The result is that Whitehead concentrates more on developing a construct for God than illuminating how the model addresses/avoids the issue of immortality. How then do we ground ourselves in this model while comforting those who are dying?

Monique

Monique was eight years old and virtually living in a big urban hospital I met her. This little girl was dying of AIDS related complications. She had apparently been

infected at conception and had tested HIV+ as an infant. Monique had been left in the care of a foster mother whose ministry was to care for children with HIV. Monique never had a lot to say. Most folks stayed away from her and the medical staff treated her with as little physical interaction as possible. Her health declined rapidly during her last days in the hospital, and she sought comfort in simply being held or touched by another human being. During her final hours, Monique's foster mother and I stayed near, comforting her as best we could. Monique fought a hard battle and restlessly released her hold on life. This little girl, born waiting to die, suffered greatly for most of her short life. "Is that all there is?"

In *God, Christ, Church*, Marjorie Suchocki writes about transformation as one of the aspects of being in relationship with God. She states that:

God feels all subjectivities in the process vision. Transformation is not restricted to humanity, but must be extended to the whole universe. There will be a new heaven and a new earth, but the locus of both is God's own being through God's power of resurrection.

This resurrection is spiritual, not material. The world is not simply transposed to God, so that it

exists in a sort of parallel state. The world is transformed in God. This is why resurrection, which connotes transformation, is a more precise term than immortality, which could simply imply continuance.⁸

Suchocki's statements about resurrection appear to be concentrated on verifying the reign of God rather than the actual issue of immortality. In a class discussion she stated that "since souls cannot just float around without bodies, God becomes the body supporting the souls of the dead. Therefore the self continues." This may be what she means by God being a home for the whole universe, a reality where eternity and history meld together.⁹

Although Suchocki's views posit a subjective immortality, her focus appears to be in developing an understanding of relationality in the process model and viewing sin from that vantage point. It is her emphasis on the relational aspect of God-creation that generates the discourse on resurrection/transformation. While this may be an essential component in comprehending immortality, immortality seems to be understood as a foregone conclusion in most process thought.

⁸ Suchocki, *God, Christ, Church*, 205-06.

⁹ Suchocki, 216, 224.

Both Ruether and Suchocki offer possibilities for expanding upon the issue of immortality, while Whitehead appears reticent to broach the subject in any explicit manner. Ruether ponders whether or not women have the same stake in denying their mortality that men do, quoting Anne Wilson Schaef:

Since White Male-System persons so firmly believe that it is possible for one to become God, they are understandably concerned with the issue of immortality. Female-System persons, on the other hand, realize that immortality is not a genuine possibility and spend little or no time worrying about it.¹⁰

Having lived and worked with so much death and dying, grieving and loss over the last several years, I must take exception to the notion that women do not ponder/worry about immortality. When people are dying they do wonder about what will happen to them. While they realize, as we all need to, that death is inevitable, the dying seek comfort from the assurance that they will continue on in some form. Marjorie Suchocki speaks of the resurrection rather than immortality, using a Christian term. Doesn't resurrection connote the ending, the finitude of a specific reality, which is replaced by another? Does the concept of

¹⁰ Ruether, 235.

immortality (subjective) flow better as an element of the process model?

It is apparent that Suchocki, Ruether, and Whitehead all believe in some form of immortality – Suchocki through the Christian construct of the resurrection, Ruether through a more agnostic ecological process, and Whitehead by simply not denying the possibility and leaving room for its interpretation as part of the process model – objective immortality.

In positing a model that incorporates immortality from a process feminist perspective, it is important to acknowledge key concepts from each perspective. Process Theology is grounded in metaphysics, and one of this science's laws is that energy cannot be created or destroyed. It can, however, be transformed. Feminist theology is grounded in experience and calls for the liberation of all. Combining these concepts lays the foundation for a process feminist model that can include dimensions of immortality, one that includes subjective experience, freedom from oppression, and a continuation of the energy that has existed.

Simply stated, immortality does not negate life as we know it. It is a continuation of the process of becoming that occurs in the realm of God, a reality that we cannot fully comprehend. Our initial aim comes from God, and, ultimately, it is to God we return. A human form, a society of actual occasions, experiences reality as concrescence, through prehensions and subjective immediacy, which concludes with satisfaction. The society of actual occasions is constantly transforming, and transformation includes the death experience. In the moments of death, our material existence is transformed to a spiritual existence in God. The physical body may, as Ruether suggests, become fodder for other material forms of existence.

As stated earlier, Suchocki uses the term resurrection when referring to this transformation from a material state into existence in God. Resurrection connotes a definite ending and a new beginning, whereas immortality assumes that we continue in process, a state of constant transformation. Suchocki's discussion of this transformation is illuminating, however. She states that transformation occurs:

...in God through the fullness of God's feeling or "prehension" of us into divine life... We are made partakers of God's life through a movement from the edges of God to the everlasting depths of God, from God's consequent nature to integration with God's primordial nature... In God there is a new fullness of relatedness to all others. The finite development of subjectivity required selectivity and a clear demarcation of boundaries. The results of the demarcation remain but the circumstances are changed. Whereas in finite existence the parameters of existence might have been the societal togetherness of many actual occasions so that a material existence developed, in God the parameters of existence are simply God. All relatedness, not some relatedness, is found in the environment of God. Therefore the subjectivities that are resurrected in God are no longer definable in terms of material togetherness. Materiality falls away, since the conditions for materiality do not exist in the single reality of God. Resurrection is to a spiritual body.¹¹

What would this look like from a process perspective?

It can be grounded in potential experience using Timothy McVeigh, the man convicted of bombing the federal building in Oklahoma City in April, 1995. Upon his death, McVeigh would be transformed into subjective energy that resides on the periphery of God. As part of the process of transforming into the depths of God, McVeigh would experience the results of his actions in Oklahoma City. He would know the dying moments of each being that perished as a result of the bombing. Through this process, which might

¹¹ Suchocki, 203-06.

be called Hell, McVeigh would experience the pain and agony he caused (judgment of God?), make retribution by living the experience(s), and continue transforming deeper into God/the divine.

Another example of this would be Mother Theresa. Hers was a life of service, living among and caring for the poor and oppressed in India. When Mother Theresa arrived at the edge of God/the divine, she would experience how her life touched others. Because her life had been dedicated to comforting others, Mother Theresa would experience the joy and peace with which she blessed others.

This might equate to our traditional understanding of Heaven. Ultimately, God/the divine may be heaven for both Timothy McVeigh and Mother Theresa. On the periphery of God each would experience the repercussions their lives had upon creation and eventually each would transform into the depths of God.

As one transforms into the multiply-conscious depths of God, one enters deeper and deeper into the primordial nature of God enhanced in wisdom. As our wisdom and experience expand (through reincarnation?), we increasingly become incorporated into the primordial nature of God.

This understanding of immortality allows for the essential ingredients of both process and feminism - energy continues to be transformed, subjectivity is grounded in experience, and the liberating effects of transforming into God are astounding.

Marjorie Suchocki states this powerfully when she writes:

There is a home in God, a home for the whole universe. In that home multiplicity finally achieves unity and fragmentation is embraced in wholeness. The unity and wholeness receiving and transforming each part is more than the sum of them all, for the unity is the ever-living God, drawing upon divine resources of infinite possibility to blend all reality into the giving and receiving of the whole. Differentiation remains in the primordial depths of God, but it is a differentiation that is divinely sustained as the most fitting actuality of unity, beauty, and wholeness: the reign of God is the reign in God, which is God.¹²

Having offered some thoughts about how a process feminist model might address immortality, it is imperative to assert that there are possibilities for addressing immortality in a process model. If we are not willing to take a leap of faith and ponder these possibilities, we are left asking 'Is that all there is?' and wondering at the

¹² Suchocki, 216

validity of Process Theology for the Christian community.

We need to remember, as John Cobb and David Griffin state:

The expression of Christian eschatology in Whiteheadian terms is still in process. There is agreement that human life is something more than a succession of events between birth and death, that God aims at personal life as the condition of intensities of experience, that God saves what can be saved. There is assurance that death and perpetual perishing are not the last word, but there remains a profound mystery, which even Whitehead's intuition could not penetrate.¹³

This mystery is addressed in a complementary way by the teachings of Tibetan Buddhism. The question "Is that all there is?" is answered with an emphatic "No" in this spiritual tradition. Tibetan Buddhism melds well on a metaphysical level with process theology by addressing the realities of death and dying directly. The Buddhist concept of "bardos," which are periods of transition between two states of existence, helps to establish an understanding of death as a transition. There are six principal bardos: life, sleep, dream, meditation, dying, dharmata (intrinsic radiance), and becoming (rebirth). We experience births and deaths throughout our life cycles - they are times of transition in our lives.

¹³ John Cobb and David Ray Griffin, *Process Theology: An Introductory Exposition* (Philadelphia: Westminster Press, 1976), 124.

Sogyal Rinpoche writes:

Contemplating deeply on the secret message of impermanence - what lies in fact beyond impermanence and death - leads directly to the heart of the ancient and powerful Tibetan teachings: the introduction to the essential "nature of mind." Realization of the nature of mind, which you could call our innermost essence, that truth we all search for, is the key to understanding life and death. For what happens at the moment of death is that the ordinary mind and its delusions die, and in that gap the boundless sky-like nature of our mind is uncovered. This essential nature of mind is the background to the whole of life and death, like the sky, which folds the whole universe in its embrace.

The teachings make it clear that if all we know of mind is the aspect of mind that dissolves when we die, we will be left with no idea of what continues, no knowledge of the new dimension of the deeper reality of the nature of mind. So it is vital for us all to familiarize ourselves with the nature of mind while we are still alive. Only then will we be prepared when it reveals itself spontaneously and powerfully at the moment of death; be able to recognize it "as naturally," the teachings say, "as a child running into its mother's lap"; and by remaining in that state, finally be liberated.¹⁴

Tibetan Buddhism teaches a practice of preparation for death known as p'howa. By using this method of transferring consciousness into an environment of enlightened awareness at the moment of death, one can bypass the karmic destiny one faces in the bardo of becoming. Bardo is the intermediate state between death

¹⁴ Sogyal, 12.

and rebirth in which different types of bardo experiences may occur. When one enters unconsciousness and reawakens to the experience of mind just as mind is, one has entered the clear-light bardo, during this enlightenment at the time of death, one can recognize the ground of absolute truth. A lesser level of enlightenment at the time of death allows the apprehension of color. If enlightenment at these two levels does not occur, one enters the bardo of becoming, sidpa bardo, which is the beginning of the karmic route to ordinary rebirth. Karma is the inexorable law of cause and effect. If one cannot understand the absolute nature of one's being, then karma will envelope one's existence and life will be measured by attachment and aversion. From the time of birth until the time of death, life experience is an ever-changing relative truth that is held to be very real. Contradictorily, it is not absolutely real or permanent. The world is simply the world and we perceive and interact with it according to our own level of understanding.

There are many ways to prepare for the transformation of death, the greatest of which results in enlightenment in one's lifetime. In enlightenment, death has no relevance

to one's state of being. If deathless enlightenment is not accomplished during one's life, the transition to death offers another opportunity. Birth, sickness, old age, and death are the four basic afflictions of the human condition. One of the greatest sufferings of sentient beings is the pain that is experienced from not getting what is desired, or getting what is desired only to discover that it is not what is really desired. These constant frustrations are intrinsic to the impermanent, changeable nature of cyclic existence.

In *No Death, No Fear*, Thich Nhat Hanh writes:

Impermanence should also be understood in light of inter-being. Because all things inter-are, they are constantly influencing one another. It is said that a butterfly's wings flapping on one side of the planet can affect the weather on the other side. Things cannot stay the same because they are influenced by everything else, everything that is not itself.¹⁵

The metaphysical aspects of Process Theology and Tibetan Buddhism allow for an understanding of spirit as energy. This energy continues after the body dies. Both schools acknowledge the continuation of the spirit - Process Theology as energy combining with the original

¹⁵ Thich Nhat Hanh, *No Death, No Fear: Comforting Wisdom for Life* (New York: Riverhead Books, 2002), 41.

source of energy (the Divine) and Buddhism as our innermost essence, through which we may attain enlightenment by uniting with the Ground Luminosity. The ultimate goal in both processes is to become more than what we are now - ultimate freedom results from letting go of all that binds us to an earthly consciousness and moving on to an inconceivable connection with our true selves/spirits in relationship to the Divine. By letting go we are able to step into the sacred space which incorporates a spirituality of dying.

By honoring the process of those for whom we care, we are reminded of the mysteries of death and life and the sacred connection which binds us all. Each day brings the possibility to celebrate the precious gift of life and the opportunity to explore our own spiritual quests and face our own mortality. We need to tell our stories about dying and living. We need to tell our stories about hope, love, and the sacred. We need to tell our stories about life after death and know that our voices will be heard.

CHAPTER 5

LIVING

The quality of presence determines the quality of life.
- Buddhist teacher Jack Kornfield¹

Perhaps it is the acknowledgement of our own mortality that encourages survivors to re-evaluate priorities and goals. In providing grief counseling to family members, I have come to appreciate how loss changes everything. The bereaved have told me how hard it is to be left behind. Even having time to prepare for a death does not mean we are fully aware of the implications until after the death occurs. Some families are very practical in their approach and have their housekeeping organized - documents, finances, and living arrangements may be all sorted out - yet the change is much more encompassing than anyone has imagined. Many bereaved have told me that it is the "little things" that can be the most devastating - automatically pouring two cups of coffee instead of one, picking up the phone to call someone who is no longer there, or simply the silence in the home that has become so

¹ Brussart, 67.

loud. We cope with death as life continues. We continue to live in the midst of incredible, life altering change.

We human animals are like any other living being, determined to survive in physical form until it is impossible for us to do so. In the previous chapter we discussed theological implications for dying and death, including the reality that to be born and to live is to suffer. How do we define "living"? Is one living right up until the very moment of death? These are the kinds of questions asked when faced with terminal illness - whether it be one's own or that of a loved one. How do we go on living in the midst of dying and how do we acknowledge dying in the midst of living?

Death is inevitable. Living is full of dying. This chapter will attempt to acknowledge that reality as well as issues of living in the face of loss, recognizing survivor's guilt, and offering a creative means for facing our own dying even in the midst of living.

When we are born we face the inevitability of dying. The moment we begin living, we begin dying. While we are dying, we are still in the process of living.

What does living mean? According to Webster's dictionary to live is:

1 : to be alive : have the life of an animal or plant
 2 : to continue alive 3 : to maintain oneself :
 SUBSIST <lived on rice and peas> 4 a : to occupy a
 home : DWELL <living in a shabby room> <they had
 always lived in the country> b : to be located or
 stored <the silverware lives here>
 5 : to attain eternal life <though he die, yet shall
 he live -- John 11:25 (Revised Standard Version)> 6 :
 to conduct or pass one's life <lived only for his
 work> 7 : to remain in human memory or record <the
 past lives in us all -- W. R. Inge> 8 : to have a life
 rich in experience 9 : COHABIT transitive verb 1 : to
 pass through or spend the duration of <lived their
 lives alone> 2 : ACT OUT, PRACTICE -- often used with
 out <to live out their fantasies> 3 : to exhibit
 vigor, gusto, or enthusiasm in <lived life to the
 fullest>
 4 a : to experience firsthand <living a dream> b : to
 be thoroughly absorbed by or involved with <she lives
 her work> ²

To live is to be in process. When and how the process of life begins are ruminations for another time as the focus here is upon living in the midst of the reality of death and dying.

Life and death are like yin and yang, two aspects that give meaning to each other. Like joy and sorrow, can we really know one without knowing the other? Most folks act as if death is optional, never coming to terms with it

² Merriam-Webster Online, s.v. "Live," 2005 ed.; accessed 20 Aug. 2005; available from <http://www.Merriam-Webster.com>.

until it is imminent, if even then. When someone is brought onto hospice service, the patient and family may have the chance to adapt to the terminal diagnosis and thereby live fully with the prospect of death and dying in their midst. It is important to acknowledge that people live with dying in many ways, from remaining in a state of denial to embracing it fully and completing life tasks. One of the most common responses to facing dying while living is grief.

The Addition of Spiritual Stages to Kubler-Ross Stages of Death and Dying

Elizabeth Kubler-Ross wrote a ground breaking work, *On Death and Dying*, in 1969. She wrote about a process through which she believed most dying individuals progress. While calling the aspects stages, Kubler-Ross admitted that individual experience is unique and that the stages are general guidelines. These stages are experienced by those living with dying, whether it is a patient or loved one. The stages are: 1) denial and isolation; 2) anger; 3) bargaining; 4) depression; and 5) acceptance.³ Kubler-Ross

³ Kubler-Ross, *On Death and Dying*, 38, 50, 82, 95 112.

uses living human documents throughout her writing to exemplify the actuality of living in the midst of dying. These stories help relate how individualized and unique the living/dying process is. People can stay in a stage, skip a stage, return to a stage, or even experience some overlap of stages when consciously facing the end of life. Survivors may even experience similar feelings during bereavement. The modern hospice movement was in its infancy when Kubler-Ross and her students studied patients in medical settings and learned that there were similar patterns of responses to death and dying. Even with advances in medical science and more options available to patients and families, the pattern of responses remains valid.

Spiritual Stages of Death and Dying

While I appreciate Kubler-Ross' work, I believe it lacks the necessary spiritual component. Kubler-Ross' stages are looked at from a psychophysical standpoint. They do not explore the spiritual. I offer the following spiritual stages of death and dying to compliment her original stages. These are: 1) faith will make you well,

2) betrayed by God, 3) bargaining with God, 4) dark night of the soul, and 5) spiritual peace.

Faith Will Make You Well

In order to cope with the shock of learning about a terminal illness, a patient, and family, may enter into a state of denial because the information is too overwhelming. It is the kind of knowledge that changes everything in the blink of an eye. Living will never be the same because death becomes very real. Human beings can go into a state of shock as a response to traumatic events and denial can be a means for mediating it. For a hospice patient and family, living with dying may begin prior to being admitted to hospice service, when they are told by a medical practitioner that there are no more curative measures to be taken. Palliative care may begin at that time and the patient may be admitted to hospice service, depending upon the diagnosis and prognosis. Imagine being told that life will never be the same again and that there are lots of decisions to be made in a very short period of time. That is the situation facing most folks when they are given the opportunity to receive hospice care. While some people have their affairs in order, very few have

given much thought to how they would like to live while dying. Most human beings live in denial of death; Kubler-Ross' stages offer a viable means for understanding the adaptation to terminal illness. It takes time to adapt to the prospect of living with dying. Some folks do not adjust and thus remain in denial throughout the dying process. This may be the only means they have for managing. As a spiritual care provider, I have experienced interactions with patients and families where everyone knows the "secret" but no one wants the other one to know because it might be too painful. Some families go through the entire dying process keeping a secret that they all know - the "elephant in the room" syndrome. Individuals in a family facing terminal illness may also vary in their process through the stages. Those close to the patient may suffer from survivor's guilt once they move from a state of denial. Survivor's guilt can create a great deal of conflict within an individual. It is a key issue to be dealt with during the grieving process and will be discussed later in this chapter.

Denial can be seen in many who believe that their faith will make them well. They believe that if they place

their trust in a higher power (God), they will be healed from their affliction. Many hospice patients and families talk about having "enough faith" and need to believe that miracles do happen. Some intensify their spiritual expressions in order to feel more connected to a God/higher power that will heal them, using objects and practices such as special oils, amulets, prayers and incantations, and laying on of hands to receive a miracle cure. Sadly, some individuals are swindled by those purporting to heal in God's name as long as a financial offering is made to further the ministry. The belief that faith will make you well may provide comfort to some, but it is also a means for judgment by others. If a believer is not restored to physical health, the believer is seen as sinful or lacking by the very people that could be an important source of support during the dying process. The dying individual may hope and pray for healing. I always encourage them to think about their understanding of healing and what it may mean in their lives. A person may not be physically cured, yet may heal broken relationships and find a sense of peace from that healing.

Frances

Frances was a seven-year breast cancer survivor when she was diagnosed with new cancer that had metastasized to her lungs and liver. She was in her early forties and had two teenage children. Frances had been a model breast cancer survivor and was very active in survivor activities. She had beat the cancer once and was determined she could do it again. Her family was very supportive and an aunt actually stayed at the home as her caregiver during the day. When I visited with Frances her hair was gone from the chemotherapy and she was still debating about whether to start chemotherapy again. She admitted to feeling tired yet spoke enthusiastically of fighting the cancer and going into remission. The hospice team knew that Frances was very ill and that she would die soon. Frances was a devout Roman Catholic who had visits from her church on a regular basis. She believed that God would heal her again and she took great comfort in that belief. Frances slipped into unconsciousness still believing she would beat the cancer. Frances' family believed that her strong faith and belief that she would be cured enabled her to live as long as she did. Frances believed her faith would make her well and died quietly holding onto that belief.

Betrayed by God

Anger is a very legitimate response to loss and can be accusatory and cathartic. A diagnosis of terminal illness can feel very unfair. The question "why me?" is generally asked by the patient, and even family members. The anger can be very destructive, encouraging abusive outlets such as alcohol and other drugs, violence, and isolation. It can also be very energizing and liberating. Dealing with this stage can be quite challenging as patients and families can be looking for someone to blame. It is important to listen and encourage folks to express their anger in constructive ways in order to minimize potentially harmful consequences. Who hasn't felt angry in response to being treated unfairly? There is irony in the fact that no one expects to die in the now; we all perceive death as lingering at some point in the future.

When the reality sets in that a disease process is terminal, many patients and families feel betrayed by God. God has let them down, they have been lied to, and the need to be angry and blame someone makes God an easy target. Many patients and family members express anxiety over being angry with God and express concern that it is wrong to feel

that way. This can be exacerbated further by feelings of guilt and shame for feeling anger at God at all. Anger at a divine power makes sense when an individual feels powerless and has expectations dashed when that divine power does not come to the rescue. One of the things I encourage people to do is to ponder their relationship with their God. What are the concepts of God that they have held during their lives? What is the anger really about? Many patients and families find themselves needing to re-examine the significance of their spirituality and find ways to create new understanding of what is happening in their lives.

Paul was a vital and active man in his mid-seventies when he became a hospice patient. He was an avid golfer and an extrovert who enjoyed life to the fullest. Paul had pancreatic cancer which was killing him very quickly. After pursuing every avenue to fight the cancer, Paul realized that he was dying. This made him angry, especially with God. Even though he was not particularly religious, Paul had always felt God had dealt with him fairly. He had a good life, retired comfortably, and had lots of loving family and friends as well as things to do. Paul was not used to being betrayed by those he trusted and

Paul put God into the category of someone he trusted. As the disease process ran its course, Paul became more and more withdrawn. He could not participate in life the way he was used to - being virile and active. Paul became surly with his family and the hospice team. When asked about his relationship with God, Paul expressed a great deal of anger and said he was not sure if there was a God. He felt extremely devastated by the shock of facing death and could not understand how God could do this to him. Paul could not make sense of his dying because he had so much living still to do and he felt betrayed by the only entity that could change the course of his life so radically - God.

Bargaining with God

When living with dying, people attempt to make all sorts of bargains to change their prospects. Bargaining with God is a big part of this stage. Fred, one of the living human documents in chapter two, bargained with God to save his wife. Fred always believed he had made a really good deal with God. Terminal illness is not something that can be bartered. Human nature encourages us to make a deal for something better than the unknown that

many fear. Some patients and families will come to terms with the inevitability of death, yet will attempt to bargain for more time, usually to complete unfinished business. Sometimes, perhaps through sheer will and determination, patients live much longer than their prognosis would suggest, even when they are actively dying. Patients have held on for family members to arrive, special occasions to occur, or significant dates to live past. This may be part of the mystery of the process of dying rather than successful bargaining for more time to live. The survivors may bargain to change places with their dying loved one, and attempt to bargain with God as well.

Most people who believe in a higher power find themselves bargaining with that higher power at some point in their lives. This is particularly true when we face the finitude of our bodily existence. The human animal is geared toward survival and, in most cases, will do whatever it takes to stay alive. Bargaining with a higher power/ God is a means for striving for life, asking for a little more time - a week, time for a last vacation, a family reunion, the birth of a child, etc. Bargaining is also a

way for us to feel we still have some control over our destiny/mortality.

Bertie

Bertie was one of the matriarchs of a very large extended African American family. Her house was one of the hubs of activity for the clan. Bertie loved her role in the family and adored them and her God. Bertie had several illnesses that were shortening her life span, with diabetes and heart disease among them. Bertie was very involved in her church and was very excited that the next family reunion was going to be held in her hometown with relatives coming from all over the country. She was looking forward to melding two parts of her world - her church and her very large family. Even though she knew she was very sick, Bertie kept saying that she told God that she could not "go until after the family leaves". The hospice team was not sure Bertie would be alive for the reunion, yet encouraged her to continue with her plans. When Bertie's family arrived, it was very apparent they would probably never see her again. The family reunion was the best one anyone could remember. Bertie was able to participate with her family and even to spend time saying goodbye. A week after

her extended family left, Bertie died peacefully, surrounded by her children and her pastor. Bertie had made a bargain with God and firmly believed that God had let her live for one last family reunion.

Dark Night of the Soul

Kubler-Ross' next stage is depression. Depression can be understood as anger turned inward. This response to terminal illness can manifest physically as well as emotionally. Individuals who are depressed have problems with activities of daily living, including eating and personal hygiene. Depression affects sleep habits, relationships, and physical well being. In patients, depression can become so overwhelming that it hastens death. In families, it can be the longest lasting and most devastating response to the death of a loved one. There are several types of depression, and the reality of imminent death can lead a patient and the family through more than one manifestation. This is perhaps the time of most deeply felt sorrow, the acknowledgement of the losses that occur with impending death. Families must plan for dealing with the dying process, possibly requesting hospice services, preplanning funeral arrangements, and completing

unfinished business. These tasks can be not only overwhelming, they can be very depressing.

An exercise that I have used with different groups, including training hospice volunteers, is a pie chart. I ask everyone to divide the pie into eight or ten pieces. They are then asked to assign to each piece the absolutely most important aspects of their lives. Some folks are challenged by this, and everyone gets a few moments to complete the task. Once they have finished, I tell them they must now eliminate, one by one, each of the aspects of the chart. This is a very difficult thing for folks to do, and some do not complete the assignment. After the exercise concludes, I explain to them that this is what dying can be like for someone who is terminally ill - losing the things in life that we treasure the most. The discussion afterward is usually very intense, with individuals admitting that they had never thought about how dying could affect them or their loved ones. As they talk about their how startling it is to eliminate everything, some cry, others feel angry, and most admit that, while the exercise is incredible, it leaves them with very mixed emotions, including how depressing this type of loss is.

This time of depression, or dark night of the soul, is a time of overwhelming despondency where one feels abandoned by God. The idea that one is either not worthy of a miracle or that God is not capable of granting one leads many individuals to feel utterly alone. The realization that death is unavoidable is a very devastating reality to most people in our culture. The realization that not even God can save someone is overwhelming. Coping with the multiple losses that occur during the dying process may make the dark night of the soul feel interminable. For some the sense of isolation and doom can be insurmountable and they may choose to withdrawal from the world.

Ray

Ray lived in a group home with several other senior citizens. Ray's wife of fifty-seven years had died recently and his family felt he could no longer live on his own. The group home was nice and the staff was very caring toward the residents. But Ray just did not seem to care about much of anything and kept to himself. He looked sad and he was sad. When he participated in life review, Ray talked about the wonderful life he had had with his

beautiful bride. Ray's children had very busy lives and visited when they could. Ray spent a lot of time alone, either in his room or in a chair on the back patio. When asked, Ray said he did not see much point in living and that nothing seemed to matter anymore. Ray was losing weight and becoming frailer by the week. God and religion were not topics Ray discussed in great detail. He would say he supposed there was a God and that he wanted very much to be with his wife again. Ray always thought he would die before she did and did not understand why she died first. Ray was experiencing a dark night of the soul where he felt empty and abandoned by God and probably every other significant being in his life. Ray's wife had died and abandoned him. His children had their busy lives and had abandoned him. He had been moved from his home of thirty plus years and felt abandoned by neighbors and friends. Ray felt especially abandoned by God because he could not make sense of his life or why things had happened the way they had. Ray's dark night of the soul led him to give up the desire to live. All Ray wanted to do was go to sleep and wake up with his wife again. Ray continued to

grow weaker and did die in his sleep, finally emerging from his dark night of the soul.

Spiritual Peace

The final stage Kubler-Ross posits is acceptance. She states that:

If a patient has had enough time (i.e., not a sudden, unexpected death) and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate." He will be able to express his previous feelings, his envy for the living and the healthy, his anger at those who do not have to face their end so soon. He will have mourned the impending loss of so many meaningful people and places and he will contemplate his coming end with a certain degree of quiet expectation.⁴

Perhaps the key to acceptance is time. If patients have enough time to grasp their reality and deal with unfinished business, they have the opportunity to ponder their futures in a different way.

This sense of acceptance can have deeper meaning if one understands that there can also be spiritual peace. This is the type of peace that Buddhism emphasizes. When one can come to terms with the realities of death and dying and finds a spiritual center out of which to understand them, it is possible to find spiritual peace. Living intentionally, conscious of the reality of death and

⁴ Kubler-Ross, *On Death and Dying*, 113.

suffering is a spiritual practice which is hard to master. Living life fully may only actually happen as we are open to facing death fully as well.

Gloria

Gloria was well aware that she had lived a wonderful life. She loved to share stories about her family, her job, and her adventures. Gloria was definitely an optimist who loved life and made the best of every situation. She resided in an assisted living facility where she was very involved and knew everyone. Gloria had been active in the Baha'i faith and had a good spiritual support system. The lung cancer that had metastasized to her bones was wearing her out. Gloria spent more time in her room and enjoyed company. She talked about her life and faith and that she was ready to die, saying that she had no unfinished business to attend to and that all loose ends had been tied up a long time ago. Gloria felt that she had lived the best life that she could and that that was good enough. She had some concerns about pain because of the cancer. The hospice team worked with her to make sure that she was kept as comfortable as possible. No matter how weak she became, Gloria always greeted everyone with a smile. When

she died, the attending nurse said she was very peaceful and had a sweet smile on her face. Gloria knew spiritual peace before and during her dying process. She had a sense of completion at the end of her journey and an appreciation for all she had seen and done, and for the companions who had walked with her.

Elizabeth Kubler-Ross pioneered the study of death and dying in modern society in ways that have brought understanding and comfort to those who are terminally ill and to those who love and care for them. Others in the field have used her model to continue to build an understanding of the dying process for patients and their families. Her work has helped the dying live well and the living mourn and heal the loss. She taught that living with dying is an ongoing process, one we become more aware of as we face imminent death. Her work has also benefited those deemed survivors - the loved ones that remain to cope with their losses and to live with repercussions of death.

In general, hospice bereavement services are offered for thirteen months after the loss of a loved one. The time spent providing care for individuals through this new phase of living is usually longer than the time spent with

the patient and family during the dying process. When one is bereaved, Kubler-Ross' stages and the spiritual stages of loss can help make sense of the grieving process after the death. Grief is something to be worked through, not gotten over. There are several aspects to living at this point that need to be considered. Grief is as unique as the individual experiencing it. While there are common manifestations of grief, social, cultural, and gender issues can make the expressions of grief appear very unique. In *Dimensions of Diversity in the Reconstruction of Meaning*, Robert Neimeyer and Nancy Keesee state that

culture is perhaps the most encompassing dimension because that is the means by which we understand language, beliefs, and social roles. They theorize that cultures effects on grieving may be invisible, especially by those subsumed by it, as culture is largely responsible for creating the set of norms that guide our living and thinking.⁵

Creating a Death Plan

One possibility for individuals to consider is creating a Death Plan. While that may sound morbid, it actually follows a typical pattern for dealing with living.

⁵ Robert A. Neimeyer and Nancy J. Keesee, *Dimensions of Diversity in the Reconstruction of Meaning*, cited in Kenneth Doka and Joyce Davidson, eds. *Living with Grief: Who We Are, How We Grieve* (Washington, DC: Hospice Foundation of America, 1998), 230.

People create birth plans upon hearing that the birth of a child is pending. Depending upon circumstances, the birth plan can be very rudimentary or very detailed. The news of the pregnancy is usually confirmed by a medical practitioner (as is the news of a terminal illness). Prenatal exams are scheduled, tests are run, the news is relayed to loved ones, and birthing and infant care classes may be scheduled. There is a great deal of planning to do, including preparation for the actual birth, and life changes forever. Creating a birth plan is common place in our society now and may include journaling, baby showers, choosing names, and additional medical procedures such as amniocentesis, genetic testing, and sonograms may be scheduled. Once the baby is born, plans for its future are made - healthcare plans such as well baby visits, childcare plans, and academic education plans. The plans revolving around the birth of a child may be part of an even bigger plan on the part of the parents, who may have a life plan or a "five year" plan of which the birth of a baby is part. So why not incorporate a death/dying plan into our plan for living?

A Death/Dying plan would incorporate the legal and health care documents people are already encouraged to complete such as wills, living wills, and durable powers of attorney. It would include preplanning for funeral and memorial services, including planning the service as well as paying for it. The funeral industry now has specialists in preplanning services that can assist with all the arrangements for a funeral or memorial, from installment payment plans to choosing music. This plan would encompass more than just the logistics of death. A death/dying plan entails more creativity and is more involved — it requires acknowledging our own physical demise before it occurs.

The starting point for creating a death plan is being able to admit to our own finitude in this particular reality. Buddhism allows for this in the intentional practice of bardo mentioned in chapter four. Living consciously with the prospect of dying can be very freeing. It can also help individuals focus time and energy on what really matters to them. Country singer Tim McGraw performs a song inspired by the experience of his father, Tug McGraw, upon learning that Tug had inoperable brain cancer.

The lyrics tell the story of a man in his early forties who finds out that he is dying.

He talks about the startling revelation that he is dying and what he chooses to do with the time he has left. He realizes he hasn't live life the way he might have and uses the time remaining to make amends, love more intentionally, and live as fully as possible. His wish for those of us listening is that we "get the chance to live like [we] were dying".⁶

As the lyrics vividly express, many of us might live differently if we fully came to terms with our mortality. The process of creating a dying plan allows one to reflect on choices and priorities and make decisions to live more fully in whatever time remains. It allows individuals the freedom to be creative in determining how to live and how to die.

In creating a death/dying plan, I offer four aspects for consideration: physical, environmental, relational, and cognitive/spiritual. The physical aspects of dying include awareness of the senses (sight, sound, touch, taste, and

⁶ Craig Michael Wiseman and Tim Nichols, "Live Like You Were Dying" perf. Tim McGraw, *Live Like You Were Dying* (Curb, 2004), compact disk.

smell). What do we want to see before we die and as we are dying? Are there places to visit, sunrises to witness, or sunsets to savor? What do we want to hear as we live and die? Are the sounds of laughter, birdsong, or rustling leaves important to us? What do we want to hear spoken to us? What kind of touch do we want to experience? Do we desire the caress of a lover, being enfolded in a parent's embrace, the tickling of a child, the feel of soft snow on our face? What do we want to taste? Do we find comfort in a traditional holiday meal, the taste of salt on our lips after an intense workout, or a freshly picked apple?

How about the physical qualities of pain and comfort? How do we define them for ourselves? What is our pain threshold, and do we seek ways to eliminate physical pain in our lives or ways to endure as much of it as possible? Pain is relative and so is comfort.

Environmental aspects of dying include our actual physical surroundings such as a home, a room, a hospital, or a cruise ship, for example. With what do we love to surround ourselves? Are candles something we light on a regular basis, on special occasions, or not at all? Do pictures of our loved ones find room in our space? Are

there certain colors that are more pleasurable than others?
Do other life forms co-exist in our environment of choice
(plants, pets, other humans)?

What are the relational elements of living that are
most precious to us? Who do we want to be present to share
life experiences, especially the most momentous ones -
family, friends, professionals (health care, financial,
etc.) spiritual leaders, the Divine? What are our
relationships like now and how would we like them to be?

The cognitive/spiritual components of a death plan
include an awareness of life as a process of which death is
a part. Would this mean introspection about the meaning of
life or perhaps a simple acceptance of the inevitable? How
do hope and faith color our understanding of dying and
living? What kind of cognitive and spiritual pain and
comfort might we find as we reflect on our own finitude?

All of these aspects are essential in creating a death
plan. How a death/dying plan is formulated is up to the
individual/family and can be as innovative as the
imagination permits. One of the most important steps in
creating a death/dying plan is to incorporate it
intentionally into the way one lives. Formulating a death

plan provides one with the opportunity to more fully acknowledge and understand his/her spirituality of dying.

By transitioning into this life we are all fated to transition out of it as well. Facing the unknown that awaits us can create anxiety and fear in some. Perhaps our fears can be assuaged by stepping into the dying process with each other and supporting one another as we deal with the losses journeying through life bring. The hospice movement is defined by its intention to provide service to those who are dying and bereaved. Spiritual care is an essential component in the provision of this support.

CHAPTER 6

A MODEL FOR SPIRITUAL CARE IN A HOSPICE SETTING

*Love and compassion are necessities, not luxuries.
Without them, humanity cannot survive.*

- ~~The~~ Dalai Lama¹

Providing spiritual care in a hospice setting is, like other forms of ministry, a vocation. It is more than a job - it is a calling. This calling helps define who I am and how I perceive reality. It means that I am much more focused on delving into the meaning and purpose of life and death than I am other pursuits. It means that I am affected spiritually by living out my calling. It means I take this calling seriously and believe in the sacred nature of relationship with all of creation, including the dying and their loved ones. It means I believe it is essential for the discipline of spiritual care to be understood as a vital force in the hospice movement. Spiritual care requires dedication and a belief in the intrinsic value in all life. In order to be acknowledged as a professional discipline on the hospice team there need

¹ Dalai Lama XIV, *Ancient Wisdom, Modern World: Ethics for the New Millenium* (London: Little Brown/Abacus, 2000).

to be a clear understanding what comprises spiritual care and how it is lived out in a hospice setting.

Creating a model for spiritual care in a hospice setting is a necessary endeavor in pushing the dialogue regarding spiritual care even further into the awareness of everyone involved in the hospice movement. For many, being placed on hospice service is equated to hearing a death knell and being visited by a chaplain/spiritual care provider can be viewed as receiving a call from the grim reaper. A large part of the task of those involved in the discipline of spiritual care in hospice is education. This education must include an understanding of the dying process, spirituality, practical applications of spiritual care, and what hospice and palliative care are. The previous chapters have delineated most of these aspects, creating a foundation on which to build a viable model for spiritual care in a hospice setting.

While the National Hospice and Palliative Care Organization has provided guidelines for spiritual care in hospice, no standards for provision have been set. A model would encourage the setting of such standards. It would be

easier to implement and maintain discipline-wide standards from a model rather than hospice agencies creating programs without direction or oversight.

What would comprise this model and what would it look like? The intention of this chapter is to put forth a model that answers this question. The model needs to be inclusive of understandings of spirituality and populations served, the composition of the hospice team, and the relevancy and necessity of a specialized discipline called spiritual care.

A Model

Minimum Requirements

The Spiritual Care Professional is mandated as a component of the core hospice team. As such the spiritual care provider must be understood as an integral, equal part of that team. The spiritual care provider needs to be accorded the same value as the other team members. The idea of the team model for hospice practice comes from a desire to share the responsibility for providing quality care and supporting each other in providing that care. All of the disciplines on the hospice team are service/care providers. The type of care each provides is based on

delineated responsibilities, training, skill sets, and education. The team must include: a medical doctor, a licensed nurse, a social worker, and a spiritual care provider. Not-for-profit hospice teams also include a volunteer coordinator and a home health aide. Additional staff and responsibilities are usually added as the patient case load increases. Staffing designations as exempt, non-exempt, full-time, part-time, and hourly are defined by each hospice.

As the hospice movement becomes more formalized, the educational requirements for staffing are becoming more stringent. The spiritual care provider needs to meet the following minimum educational requirements: Master of Divinity degree from an accredited graduate institution (seminary, school of theology, or school of divinity); a course of study that includes an emphasis in pastoral care; a minimum of one unit of clinical pastoral education for an entry level spiritual care position (advanced standing in the Association of Clinical Pastoral Education would be preferred), and some form of field education completed in a specialized ministry position.

Endorsement by one's ecclesiastical body needs to be mandated so that there are parallel systems of accountability and support for the spiritual care provider. Most forms of endorsement require ordination as clergy by the ecclesiastical body, although exceptions might be made for candidates who may not be ordained because of cultural or gender biases. These individual could obtain special waivers, provided they met all of the other requirements. Attaining credentials as a certified chaplain is also strongly recommended. National certifying agencies include: Association of Professional Chaplains, National Association of Catholic Chaplains, and the National Association of Jewish Chaplains. All of these organizations require examination as part of their accrediting process as well as meeting a minimum standard of academic education and pastoral experience.

It is essential that spiritual care providers who work in hospice have a strong background in pastoral/spiritual care. This needs include academic course work, specialized field education experiences, and actual spiritual care work experience. Competency in pastoral counseling is highly recommended and may be achieved through a combination of

academic course work, work experience, and continuing education. Continuing education for spiritual care providers must be mandated and supported by the hospice movement. Other professionals (nurses, social workers, and doctors) are required to complete a certain amount of continuing education following specific guidelines. There are no minimum continuing education requirements (or credits) for spiritual care providers. It is also difficult to find programs that offer continuing education units to spiritual care providers.

A spiritual care provider in a hospice setting is obliged to be spiritually mature. Spiritual maturity is not necessarily equated with chronological maturity. Spiritual maturity for hospice care dictates that one be comfortable with one's own sense of spirituality and open to diversity in others as well as the ability to cope with end of life issues.

Role on the Hospice Team

The role of the spiritual care provider can vary, depending on several factors such as patient census, delineation of job responsibilities, understanding of the

position, and level of skill and experience. Most individuals perceive the spiritual care provider as someone who prays and facilitates rituals such as funerals and memorial services. According to NHPCO guidelines, a full-time spiritual care provider is required for an active patient census of forty to sixty individuals. The frequency of visits to patients and families varies according to need and is usually set at between one and three visits per month. Some patients and families require more visits and others want none at all. Spiritual care providers need to be the team members responsible for conducting spiritual assessments as well as making referrals to patients' spiritual leaders. This task should not fall to nursing or social work staff. Assessment of one's spiritual needs, concerns, and well being are as important as assessment of one's physical or social needs.

While patient care is the primary focus of the team, it is important for the spiritual care provider to provide care and support to the hospice team members and support staff as well. The nature of hospice work dictates that there will be emotional and spiritual care concerns experienced by individuals and, at times, the entire team.

The spiritual care provider may facilitate staff support groups, individual counseling, referrals, and interventions.

The spiritual care provider can offer continuing education to other staff in the areas of spiritual care and other areas of expertise (history of religion, world religions, theology, etc.) as a means for garnering greater understanding of spiritual care by other team members and even members of the larger community. Providing educational opportunities can be of benefit to the hospice and its community by providing bridges of understanding and support. It is important that spiritual care providers network with other clerics in the larger community. This will provide a web of support to the spiritual care provider, connection with patients' spiritual leaders, and offer opportunities to educate colleagues about the unique vocation that exists in a hospice setting. By networking, the spiritual care provider can encourage the larger religious community to support the work of hospice as a local mission or with volunteers. It is also an excellent means for letting people know that there is a vehicle of support for the terminally ill in the community.

Depending on the structure of the hospice, the spiritual care provider may be responsible for bereavement services as well as spiritual care services. Bereavement guidelines require that thirteen months of support be provided for the patients' loved ones. A spiritual care provider may make phone calls, provide supportive mailings, facilitate support groups and individual bereavement counseling, conduct funerals and memorial services, and facilitate hospice memorials/commemorations.

A spiritual care provider may also be required to be on-call and available to assist in crisis situations and attend deaths. There may be "walk-ins" who stop by a hospice facility to seek support without having scheduled an appointment. People who walk in usually need some type of immediate support, whether it's a hospice referral, referral to another community agency, a listening ear, or simply a shoulder to cry on.

Types of Spiritual Care Provided

Spiritual care in a hospice setting encompasses a great deal. Most folks think that a spiritual care provider's main function is to pray. While that may or may

not be true, there are many facets to spiritual care.

Prayer, both public and private, spoken and unspoken, is integral to the discipline of spiritual care. Providing spiritual care, however, does not stop there. Depending upon education and training, spiritual care can incorporate some innovative components. Healing/therapeutic touch, offered by a trained spiritual care provider, can provide a patient with a sense of physical, emotional, and spiritual comfort. By virtue of being open and non-judgmental, a spiritual care provider can proffer the ability to be fully present and listen with compassionate care. An understanding of thanatology and a grounding in one's own spirituality enable a spiritual care provider to journey with patients and families through the dying process without having a personal or professional agenda. One of the most important services a spiritual care provider can offer is simply being fully present in the moment.

Encouraging a patient/family to participate in life review is beneficial in building relationships, encouraging people to see the value of their lives and sharing the sacred. A spiritual care provider might use guided imagery techniques or rituals and symbols to provide comfort to a

patient/family. Guided imagery can permit one to connect with aspects of self/spirit in a different way and rituals and symbols encourage the expression of the self/spirit in tangible ways. The types of spiritual care provided are only limited by the abilities of the spiritual care provider, the needs of the patient/family, and the structure of the hospice organization.

Spiritual Care in the Structure of Hospice

Spiritual care is defined by those who practice it, those who oversee the practice, and those who mandate the practice. Spiritual care is central to a healthy, functional hospice organization. The place of spiritual care may vary depending on the size of the hospice, the patient census, and, perhaps most importantly, the value given it by the hierarchy of the hospice. As a form of patient care service, spiritual care can be overseen by someone who supervises all patient care services. If nursing and social work are deemed separate areas, with separate oversight, spiritual care must be afforded the same respect. As responsibilities become more specialized,

spiritual care requires as much attention and consideration as other disciplines on the hospice team.

A model for spiritual care in a hospice setting has to consider the role of the discipline, recognize the value of spiritual care as an integral part of hospice service, and demonstrate respect for the professional nature of those who practice it.

Practical Application

Spiritual care providers practice in a variety of ways in a variety of settings. The process begins when a patient is admitted to service and initial assessments are done. Spiritual care providers need to be responsible for spiritual care assessments. These assessments determine the patient's/family's faith tradition, practice, concerns, and need for services. Once a patient has been assessed and desires spiritual care, a visit frequency needs to be set. Frequency should be based on the individual patient's needs and can vary from once a month to once a week. Visit duration is also dependent on patient needs. Someone with dementia who is pleasantly confused will require a different focus and amount of time than someone who is in a

spiritual or family crisis. Visits average between a half an hour and two hours with the typical visit at about an hour.

The types of services spiritual care providers offer are also dependent upon the needs of the patient and family. Services include prayer, sacraments, reading, singing, life review, pastoral counseling, theological discussion, and ministry of presence. Some patients want focused visits with prayer and scripture readings as the heart of the visit. Others like to spend time being listened to and participating in life review. The emphasis is on being present in meaningful ways for the patient and family. This is a very spiritual endeavor.

Spiritual care providers are also asked to participate in the rituals of patients' faith traditions. This might include providing communion, offering the Sacrament of the Sick, anointing, blessing a home, laying on of hands, or smudging/cleansing a space. There are rituals for which other spiritual care providers may be needed (priests, shamans, and monks for example) and the spiritual care provider may act as a conduit for the patient/family and their religious body.

It is essential to approach this vocation with the conscious intention to do no harm. Spiritual care providers must meet patients and families where they are in their faith journeys. It is imperative that the spiritual care provider does not impose his/her own tradition/spiritual agendas on the patients or families. Spiritual care must always be provided with a sense of love and compassion. The journeys we take with the dying and their families are sacred. The gifts, skills, and education required for spiritual care provision enable us to walk on hallowed ground.

CONCLUSION

It has been an intense, amazing journey. These pages contain a celebration of hospice, the opportunity to learn about accompanying the dying and their loved ones. I have provided information about the dimensions of dying and living on hospice care from social, physical, and spiritual perspectives.

There are many wonderful things that the hospice movement does well - honoring an individual's right to maintain the highest quality of life possible, to ease suffering, and to respect the dignity and sacred nature of every patient and family.

There are areas where the hospice movement has the opportunity to grow. One of those areas is spiritual care. One of the reasons creating a model of spiritual care is so important to me is because I have learned how little others, including my hospice colleagues, understand about spiritual care. Most of the writings by social workers and nurses emphasize how those disciplines need to become more adept at spiritual assessment and providing spiritual care. As an apologist for my discipline, I would suggest that

this would be akin to clergy attempting to assess and provide for medical needs. All disciplines need to understand how the others function, and acknowledge that there may be overlap in providing service. As the hospice movement becomes more bureaucratic, considering someone without specialized training to be appropriate in any discipline is no longer acceptable.

Spiritual care providers have a valuable role on the hospice team. Hospice began as a form of spiritual care. As the movement becomes more professional, it appears to be becoming more and more medical model oriented. With the physical needs of the patient becoming the sole focus of care, a relegation of the spiritual and emotional needs as secondary concerns has emerged as secondary concerns. The pioneers of the modern hospice movement believed that spirituality and spiritual care were essential components of hospice care because death and dying are the purview of spiritual care providers.

It is essential that the voices of professional spiritual care providers be heard. There is much to be learned from those that have acquired the unique academic

and experiential training that professional spiritual care providers are required to obtain.

To journey with another through the realm of death and dying is a sacred endeavor. To confront the realities of death and dying and contemplate the spiritual process of dying continues to challenge professional spiritual care providers. Touching the realm of "mystery" with the dying is an awesome and humbling undertaking - one which must always be acknowledged with reverence. The hospice movement needs to maintain awareness of its ongoing purpose - to support individuals in dying with comfort and dignity and acknowledging this as a sacred, spiritual act.

Perhaps the most important reason for this journey is to seek understanding for ourselves, to live with hope, to be faithful, and to honor the whole process of dying and living.

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